

GRANDPARENTS RAISING YOUNG GRANDCHILDREN WITH DISABILITIES  
OR AT RISK FOR DISABILITIES: THEIR DEMANDS, CAPABILITIES, AND  
ADAPTATION

By

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ADAPTATION

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The purpose of this study was two-fold. To investigate the relationship between the demands, capabilities, and adaptation of grandparents raising young grandchildren with disabilities or at risk for disabilities and to make inferences about Family Systems Theory as operationalized by the Family Adjustment and Adaptation Response (FAAR) Model in regards to a nontraditional family structure--the custodial grandparent and grandchild family. Participants of this study consisted of grandparents, residing in the state of Florida, with primary caregiving responsibility for grandchildren ages birth through 5 years with disabilities or at risk for disabilities who are receiving services from the Department of Health and Rehabilitative Services or are members of local grandparent organizations. The *Family Needs Scale*, *Family Supports Scale*, and *Family Adaptation and Cohesion Evaluation Scale (FACES) II*, as well as a questionnaire of grandparent and grandchildren demographic information, were completed by the grandparents.

The results of this study are presented in three major sections. First, data are presented which describe the sample. Second, the scaled scores for the *Family Needs Scale*, the *Family Support Scale*, and the *Family Adaptation and Cohesion Evaluation Scales II*. are presented. Last, results of the statistical analyses for each hypothesis are presented.

Results of this study indicate that grandparent and grandchild characteristics, as a unit, are not related to custodial grandparents' needs or capabilities. However, custodial grandparents' adaptation is related to grandparent and grandchild characteristics.

One component of the FAAR Model, capabilities being used to balance needs, did not hold for the custodial grandparents in this study. Custodial grandparents' capabilities were determined to be independent of their needs. Custodial grandparents' adaptation was related to their needs and to their capabilities.

The Family Systems Theory, as operationalized by the FAAR Model, held for the custodial grandparents in this study with one exception, that capabilities and needs are independent of each other. Therefore, I determined that Family Systems Theory is applicable to custodial grandparents raising young children with disabilities or at risk for disabilities.

## CHAPTER ONE STATEMENT OF THE PROBLEM

### Introduction

Professionals in the field of early childhood special education (ECSE) have adopted a family systems approach to family-centered services for young children with disabilities or at risk for disabilities. The demands, capabilities, and adaptability of families of young children with disabilities and at risk for disabilities have been studied in order to develop and implement effective and efficient individualized family support plans (IFSP) and individualized educational programs (IEP). However, the majority of research on families of young children with disabilities or at risk for disabilities focuses on the traditional family without considering the variety of viable family forms.

Hanson and Lynch (1992) noted that the proportion of nontraditional families is on the rise. Today's family units are characterized by a wide range of combinations of individuals who may be closely or loosely affiliated with one another. The number of alternative family structures includes single parent, step and blended, adoptive, foster, grandparent, and same-sex partners rearing children. According to Hanson and Lynch,

These structural changes in what has been described as the cornerstone of the American way of life have had, and will continue to have, an impact on the way that services for young children who are at risk or disabled and their families are designed and delivered. (pp. 288-289)

The current service delivery system was designed chiefly to serve two-parent families of Anglo-European descent (Hanson & Lynch, 1992). This is no longer the description of the typical American family. For example, it has been

estimated that 3.2 million children currently live with their grandparents or other relatives; this represents a 40% increase since 1980. In approximately one-third of these households neither parent is present, and the grandparent assumes the role of primary caregiver to his or her grandchildren (Brokaw, 1993; Brooks, 1994). In the state of Florida, nearly 260,000 children live with other relatives. The majority of these other relatives are grandparents (Brooks, 1994).

The American Association for Retired Persons (1993) reported that grandparents as surrogate parents represent all socioeconomic levels and all ethnic groups. Grandparent caregivers may face legal and social problems. They may lack support and respite services, affordable housing, access to medical services, and coverage of medical expenses. They may also have inadequate financial resources to provide care for their grandchildren. Not all grandparents have legal custody of their grandchildren; therefore, they receive no public assistance or insurance coverage for the grandchildren they are raising. Special medical or learning needs of some of these children may put an additional financial and emotional strain on grandparents acting as surrogate parents. A major theme reported by grandparents who had legal relationships with their grandchildren or had grandchildren living with them was that this was not a situation for which they had planned (Focus on Research, 1992b).

Cherlin and Furstenberg (1986) described the norm of noninterference, a universal norm for grandparenting which holds that although grandparents are expected to be available as a source of support during times of crisis, they are not expected to interfere in the raising of grandchildren. Although many variables mediate the relationship between grandparents and grandchildren, the norm of noninterference appears to be an underlying foundation.

Differences occur in exchanges between grandparents and grandchildren. These differences are explained, in part, by factors which have been identified through research. Some factors affecting grandparent-grandchildren exchanges include grandparents' age, age of entry into grandparenthood, gender, race, marital status, health status, socioeconomic status, and lineage connection to the grandchild. The relationship between grandparents and grandchildren is also affected by the age and gender of the grandchildren. Although researchers have investigated the relationship between grandparents and grandchildren, research on grandparents as custodial caregivers is sparse. Therefore, it is unclear what, if any, relationship exists between these mediating factors and the demands, capabilities, and adaptability of custodial grandparents. Early childhood special education personnel must understand the unique demands, capabilities, and adaptations of grandparents raising young grandchildren with disabilities or at risk for disabilities, the relationships between their demands, capabilities, and adaptation, and the mediating factors in order to deliver effective and efficient services.

#### Purpose of the Study

The purpose of this study was two-fold: first, to investigate the relationship between the demands, capabilities, and adaptation of grandparents raising young grandchildren with disabilities or at risk for disabilities and grandchildren and, second, to challenge Family Systems Theory and the operational FAAR Model in regards to a nontraditional family structure--the custodial grandparent and grandchild family. Factors that affected the demands experienced by and the capabilities of custodial grandparents were identified. The effect these factors had on the custodial grandparents' adaptability was also explored.

### Questions the Study Answered

This study answered the following questions:

1. Do the custodial grandparents' age, age of entry into grandparenthood, gender, race, marital status, health status, socioeconomic status, or lineage connection to the grandchildren, and grandchildren's age or gender have an affect on the demands custodial grandparents experience?
2. Do the custodial grandparents' age, age of entry into grandparenthood, gender, race, marital status, health status, socioeconomic status, or lineage connection to grandchildren, and grandchildren's age or gender have an affect on the capabilities of custodial grandparents?
3. Do the custodial grandparents' age, age of entry into grandparenthood, gender, race, marital status, health status, socioeconomic status, or lineage connection to grandchildren, and grandchildren's age or gender have an affect on the adaptability of custodial grandparents?
4. What is the relationship between custodial grandparents' demands, capabilities, and adaptability?

### Procedures for Implementing the Study

Potential respondents were solicited from participating Health and Rehabilitation Service (HRS) districts and grandparent organizations in the state of Florida. Initially, 200 surveys addressing the respondents' demands, capabilities, and adaptability were disseminated to each selected potential respondent by either the HRS district or the grandparent organization. Included in the packet were a letter of informed consent that explained the purpose of the research study and the measures taken to protect the respondents' identity, a demographic information survey, and three questionnaires: the *Family Needs Scale* (Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1988) which measured the grandparents' perceived demands, the *Family Support Scale* (Dunst,

Trivette, & Jenkins, 1988) which measured the grandparents' perceived capabilities, and the *Family Adaptation and Cohesion Evaluation Scales (FACES) II* (Olson, Portner, & Bell, 1982) which measured the grandparents' perceived adaptation. A separate and confidential list of respondents' names and mailing addresses with an assigned identity code was maintained by the assigned agency contact person. Self-addressed return envelopes were included with each survey for the respondents' convenience. Four weeks after the initial mail-out, reminder postcards were mailed to potential respondents who had not returned their packets. Five weeks after the initial mail-out second reminder postcards were mailed to packet recipients who had not returned their packets.

This procedure differed slightly when I met with the grandparent groups prior to dissemination. On those occasions, I explained the purpose of the study, how the results would be used, and distributed survey packets directly to the participants. However, I did not collect personal information from the recipients. The group facilitator recorded the names and addresses of the persons present and the identification numbers of the packets they received. The group facilitators also acted as the contact person for all follow-up.

Due to the low return rate on the initial 200 surveys, additional surveys were disseminated to previously untapped HRS districts. The procedure of dissemination and tracking remained the same. However, the first reminder postcards were mailed after 10 days. Rather than sending second reminder postcards, a second copy of the survey and a new cover letter were mailed 15 days after the initial mailing. Finally, the data collected in the surveys were analyzed with regard to the research questions.



### Scope of the Study

The scope of this study was delimited in five ways. First, the information gathered in the study was used to confront the Family Systems Theory and the Family Adjustment and Adaptation Response (FAAR) model in regards to a nontraditional family type and not to generalize from the sample to a population. Second, the study was delimited by geographical restrictions to the state of Florida. Third, the subjects in this study were grandparents who are raising young grandchildren, ages birth through 5 years, with disabilities or at risk for disabilities. Grandparents to be included in the study were recruited from clientele receiving services from HRS and grandparent support groups throughout the state. Fourth, surveys were disseminated and collected through the mail or organized grandparent support groups. I had no personal contact with the respondents other than soliciting participation at grandparent support group meetings. Fifth, questionnaires with Likert-type responses presented grandparents with lists of statements to which they were asked to choose the response that best represented their perception of their families' demands, capabilities, and adaptability.

The scope of this study was limited in the following ways:

1. Data were collected from custodial grandparents of young children with disabilities or at risk for disabilities only. Results, therefore, are not generalizable to other custodial relatives, custodial grandparents of older children, custodial grandparents of young children without disabilities or not at risk for disabilities, or noncustodial grandparents of young children with disabilities or at risk for disabilities.
2. Survey packets were disseminated through two channels: by HRS and by organized grandparent support groups. Direct control over the randomized selection of survey recipients was, therefore, limited.

3. Information was collected through mail-survey strategies and is limited by the respondents' ability to read and comprehend the content of the questionnaires and self-selection bias.

#### Definition of Terms

The following definitions are used throughout this study:

Adaptability is the extent to which the family's system is flexible and able to change. Adaptability includes the ability of the family system to change its power structure, role relationships, and relationship rules in response to demands and developing stress. In this investigation adaptability is measured with the *FACES II*.

At risk for disabilities is defined as being at risk of having substantial developmental delays if early intervention services are not provided. Biological and other factors that can be identified as placing children at risk for developmental delays are considered risk factors. At-risk factors include low birth weight, respiratory distress as a newborn, lack of oxygen, prenatal exposure to alcohol and other drugs, and infection. At-risk factors do not predict the presence of a barrier to development, but they may indicate children who are at higher risk of developmental delays than children without exposure to these conditions.

Capability is a potentiality the family has available to them for meeting demands. Two major types of capabilities are resources, which are what the family has, and coping behaviors, which are what the family does. In this investigation demands are measured with the *Family Support Scale*.

Cohesion is the degree to which family members are separated from or connected to their family, the emotional bonding that family members have towards one another. In this investigation cohesion is measured with the *FACES II*.

Coping behavior is a specific effort by which a family, its subsystems, or individuals in the family attempt to reduce or manage a demand.

Crisis occurs when the nature or number of demands exceed the existing capabilities of the family, and this state of imbalance persists. Crisis is characterized by disorganization and disruption within the family, and old patterns and capabilities are no longer adequate.

Custodial grandparent is a grandparent with whom a child lives and who acts in the place of a parent (even though the parent may be present in the household). For the purposes of this paper a custodial grandparent does not have to have legal custody for the child's welfare.

Demand is a stimulus or condition that produces or calls for change in the family system. In this investigation demands are measured with the *Family Needs Scale*.

Disability is a developmental delay, as measured by appropriate diagnostic instruments and procedures, in one or more of the following areas: (a) cognitive development, (b) physical development, including vision and hearing, (c) communication development, (d) social or emotional development, or (e) adaptive development. Disability is also defined as having a diagnosed physical or mental condition that has a high probability of resulting in developmental delay.

Resources are physical, psychological, and social characteristics, systems, or competencies available to a family, its subsystems, or individuals in the family with which they attempt to reduce or manage demand.

Strain is a condition of felt tension, within the family system, that is associated with the need or desire to change something.

Stress(or) is a life event that occurs at a discrete point in time and produces an actual or perceived demand-capability imbalance within the family system.

Subsystem is a system smaller than the family system. For example, the parents are a subsystem of a family. Other examples of subsystems include siblings, parent and a specific child, and parent and nonparental spouse.

Suprasystem is a system larger than the family system that interlocks with the family system and other suprasystems. For example, the church is a suprasystem of a family. In nuclear families, the extended family would be considered a suprasystem.

### Overview

A review of the relevant research and related literature is presented in Chapter Two, including the theoretical and conceptual models for this investigation; the demands, capabilities, and adaptability of custodial parents of children with disabilities; the demands, capabilities, and adaptation of custodial grandparents of young children without disabilities; the demands, capabilities, and adaptation of custodial grandparents of young grandchildren with disabilities or at risk for a disability; and the mediating factors of the relationship between grandparents and grandchildren. Chapter Three includes the null hypotheses, a discussion of the nature of the participants, a review of the current status of family assessment instruments, and a description of methodology, procedures of the study, and treatment of the data. Results of the study are presented in Chapter Four, and discussion of the results and their implications compose the fifth and final chapter.

## CHAPTER TWO REVIEW OF RELATED LITERATURE

### Introduction of Related Literature

The purpose of this chapter is to review the relevant literature related to custodial grandparents of young children with disabilities or at risk for disabilities. First, Family Systems Theory and the Family Adjustment and Adaptation Response (FAAR) Model are presented as the theoretical and conceptual foundations for the study of grandparents raising young grandchildren with disabilities or at risk for disabilities. Second, I reviewed the literature pertaining to parents of children with disabilities or at risk for disabilities. This literature is presented as it relates to the demands, capabilities, and adaptation of parents. Third, the changing demographics of families are reported. Fourth, studies of custodial grandparents are presented. Fifth, studies of custodial grandparents of young children with disabilities or at risk for disabilities are discussed. Finally, the literature is reviewed for factors mediating the grandparent-grandchild connection.

Family Systems Theory helps to explain the effect and mutual influence the family's subsystems and suprasystems have on the family as a system. These subsystems and suprasystems may be perceived by the family as either a demand or a capability with which to meet their demands. The FAAR Model focuses on the family system and its efforts to maintain balanced functioning by using its capabilities to meet its demands. Families typically go through cycles of adjustment, imbalance, and readjustment. However, when crisis occurs, families may not be able to adjust their demands with their capabilities. In such

cases, families' subsystems, system, or suprasystems may undergo change, or adaptation, in order to balance demands and capabilities.

The demands and capabilities perceived by parents of children with disabilities do not differ, in general, from those of parents of typically developing children. Neither do parents differ in their general adaptation to children with disabilities. However, changes in the structure and composition of families may result in changes in their perceptions of their demands and capabilities. For example, parents may transfer primary caregiving responsibility for their children to the children's grandparents. This new family may experience a change in its resources and sense of well-being as well as in its demands. The capabilities custodial grandparents have with which to meet these demands may be limited. The difficulties custodial grandparents experience with their grandchildren may be explained by the same factors which mediate the typical grandparent-grandchild connection.

#### Criteria for the Selection of Literature

Criteria were established to guide the selection of literature. All searches were restricted to English-language-only papers and publications printed from 1983 to the present. In addition, searches focusing on families of children with disabilities, custodial grandparents, and the grandparent-grandchild connection were restricted to empirical studies and research based on persons living in the United States. These criteria were established to assist in selection of literature that most accurately reflects the state of today's American families and the population addressed in this study. Studies of families of children with disabilities and of custodial grandparents were narrowed to investigations of their demands, capabilities, and adaptation. The grandparent-grandchild connection literature was limited to analysis of the factors mediating the connection. Literature searches focusing on Family Systems Theory and the

FAAR Model included explanatory pieces. Literature focusing on the changing definition of families included data representing statistical trends in the demographics of the population of the United States. References were obtained through a search of LUIS, ERIC, Sociology Files, and Dissertation International Abstracts at the University of Florida and through other professionals in the field. Professional literature was included if in the investigator's judgment the information provided a valuable contribution towards understanding custodial grandparents raising young children with disabilities or at risk for disabilities.

### Theoretical and Conceptual Foundation

The interconnectedness of individual family members, the family, and persons and agencies in the family's environment is the basis of a family-focused approach to early intervention. Custodial grandparents and their young grandchildren with disabilities or at risk for disabilities constitute an increasing number of the families seen in early intervention programs. The theoretical and conceptual foundation for studying custodial grandparents of young children with disabilities or at risk for disabilities is established by the Family Systems Theory and the FAAR model.

### Family Systems Theory

Whitchurch and Constantine (1993) noted that behavior occurring at any of the levels (subsystem, system, or suprasystem) of a system generally affects every other level of the system. The family system may consist of subsystems of parents, siblings, or parent and sibling and suprasystems of extended family, friendship networks, as well as other groups. By identifying the components of a family system, boundaries can be drawn between what is included in the subsystems, system, and suprasystems. All family systems have some degree of transaction with and between their subsystems, suprasystems, and

environment. Identifying the degree and direction of transactions within a family's systems network can assist in understanding the family's boundaries and openness to communication between their systems' levels and their environment. The concepts of boundaries and system openness are operationalized by assessment of the family's adjustment and adaptation. The boundaries of and interactions between a system's levels and environment are illustrated in Figure 1.

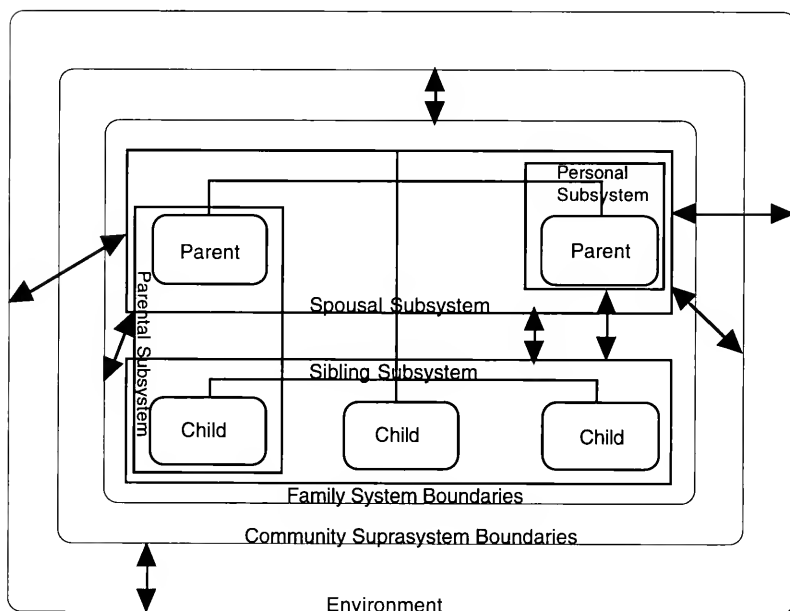


Figure 1. Family System Boundaries

Systems characterized by open boundaries have the ability to communicate within and between each of their levels and their environment.



This communication and its organization may operate to restore or maintain balance. Systems may respond to internal or external demands by acting to reduce the deviation from their prior state of balance. Such systems are considered resistant to alteration. Components of resistant systems try to maintain their transactional patterns often resulting in a lack of adjustment or adaptation to the systems' internal or external demands. On the other hand, systems may alter their own structure. For example, the family system may be altered when two single-parent family systems merge. Such systems show more variability and, if the variability is uncontrolled, may be unstable. To ensure the survival of the entire system, systems must balance their resistance to change and their impulse to change. Families' ability to communicate effectively and efficiently with and between their subsystems, suprasystems, and environment facilitates their adjustment or adaptation to their perceived demands and capabilities. The FAAR model (Patterson, 1988, 1993) illustrates the cyclic nature of family adjustment as well as the deeper changes required for adaptation in order to restore balance to the family system.

#### Family Adjustment and Adaptation Response Model

All families experience demands (stressors and strains) and have access to capabilities (resources and coping behaviors) with which to meet these demands. Balancing their demands with their capabilities requires either adjustment or adaptation of their family system. The FAAR Model (Patterson, 1988, 1993) provides a theoretical framework for understanding the families' adjustment or adaptation. In this model, three factors affect family adjustment or adaptation: demands on the family, family capabilities with which to balance these demands, and the meaning the family attaches to their demands, capabilities, and to the crises it experiences.

According to Patterson (1988, 1993) demands, or needs, are defined as the stimuli or conditions that produce or call for change in the family system. Certain personal characteristics may also function as demands upon the family. Sources of need can be from the personal subsystem, the family system and its subsystems, or the suprasystem levels. Individual characteristics such as the grandparents' age, health, and gender and the grandchild's age could be needs from the personal subsystem level while their marital status could be needs from the family system level (Patterson, 1988). The sources of needs measured by the FNS are from all three levels of the family system (see Table 1).

Table 1

Source Levels of Needs on Family Needs Scale

Personal Subsystem	Family System And Subsystems	Suprasystem
Basic Resources	Basic Resources	Basic Resources
Specialized Child Care	Specialized Child Care	Specialized Child Care
Personal And Family Growth	Personal And Family Growth	Personal And Family Growth
Financial And Medical Resources	Financial And Medical Resources	Financial And Medical Resources
Meal Preparation	Child Education	Child Education
Future Child Care	Meal Preparation	Future Child Care
Household Support	Future Child Care	Household Support
Financial Budgeting	Household Support	Financial Budgeting
	Financial Budgeting	

Capabilities consist of resources and coping behaviors. Resources are what the family has to help them balance their needs. Resources are available from the individual, the family system or subsystems, or the suprasystem. The FSS measures resources at the subsystem, system, and suprasystem levels (see Table 2). The meanings families ascribe to these demands and to their capabilities are critical factors in achieving balance. Families must achieve balance not only between their demands and capabilities but also between their resistance to change and their impulse to change. The outcome of the families' efforts to achieve balance and ensure survival is conceptualized in terms of family adjustment or adaptation. Families typically undergo a cycle of disrupted balance and reestablishing balance. This is termed adjustment.

Table 2

Source Levels of Capabilities on Family Support Scale

Family System and Subsystems	Suprasystem
Informal Kinship	Professional Services
Spouse or Partner Support	
Social Organizations	
Formal Kinship	
Family Cohesion	
Family Adaptability	

Family adjustment denotes a relatively stable period during which only minor changes are made in families' systems as they attempt to meet their demands with their existing capabilities. Patterns of interaction within and

between the system levels are predictable and stable during adjustment. Families try to deal with new demands through avoidance of the demand, elimination of the new demand or other preexisting demands, or assimilation of the demand. The process of adjustment is illustrated in the following vignette. A family consisting of a husband and wife is experiencing the demands of the husband's unemployment and their adult daughter's divorce. The family adjusts to these demands by eliminating unnecessary purchases and travel to cut their expenses and turning to their friends for emotional and moral support. This family system has adjusted to its new situation. However, when the husband becomes ill, their flexibility and friends are no longer enough to assist them in adjusting to their demands. In order to achieve balance between their demands and capabilities, the husband uses his Veterans benefits at the local Veterans Administration Hospital for treatment of his illness. The family readjusts to its situation. Figure 2 illustrates this cycle of adjustment, unbalance, and readjustment.

Changes made by families in the adjustment phase do not affect the family structure. Families in the adjustment phase only slightly modify their patterns of interaction. During adjustment, families perceive their capabilities to be adequate to meet their demands as they arise. However, the typical cycle of adjustment is disrupted when families perceive that their demands exceed their existing capabilities. At this point the introduction of a crisis disrupts and disorganizes families. During crisis, families' old patterns and capabilities are no longer adequate to restore balance.

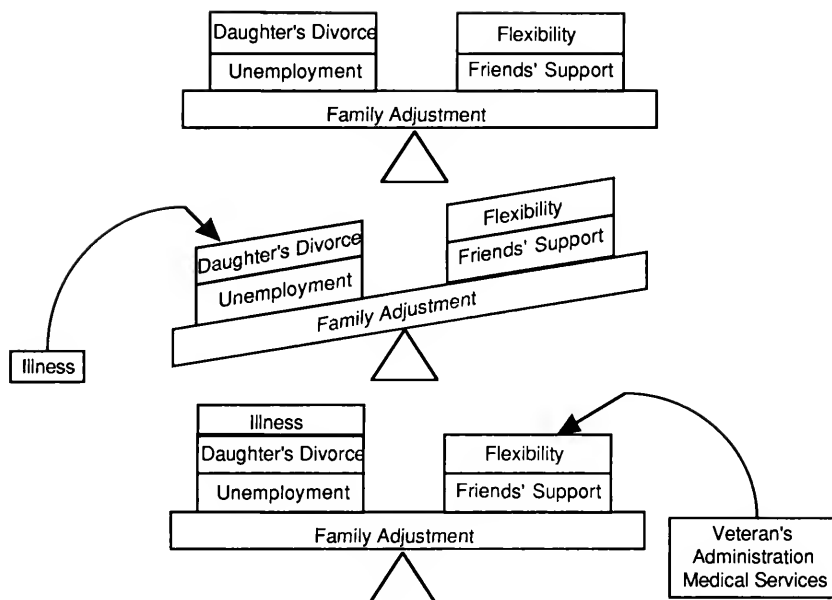


Figure 2. Cycle of Adjustment

For example, the husband and wife in the first vignette have adjusted to their daughter's divorce and the husband's unemployment and illness. However, they are concerned for their adult daughter who is having difficulty adjusting to her divorce and is neglecting her two children. After much discussion the husband, wife, and divorced daughter decide that it would be best if the parents take over primary responsibility for the care of their two grandchildren. At this point the modifications the husband and wife made during adjustment and readjustment are no longer adequate to meet their new

demands associated with these new responsibilities. The family has experienced a crisis which requires that they undergo the deeper changes characteristic of adaptation to achieve balance. Figure 3 illustrates the role a crisis plays in a family's transition from adjustment to adaptation.

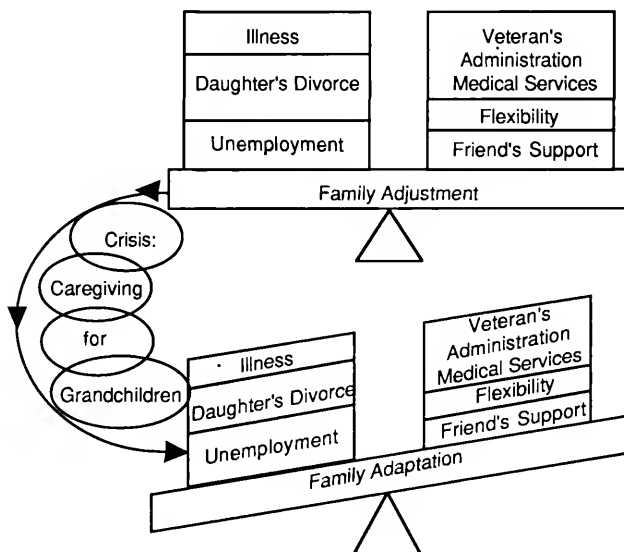


Figure 3. Transition from Adjustment to Adaptation

During adaptation, families attempt to restore balance by (a) altering or expanding their definitions and meanings to fit their changed circumstances, (b) reducing pileup of demands, or (c) developing and acquiring new capabilities. Changes made by families during adaptation involve changes in family roles, rules, patterns of interaction, and meanings. Families use capabilities from their subsystems, system, suprasystems, and environment in their attempt to adapt. The grandparents in our vignette discovered that their flexibility, friends' support, and medical services provided by the Veterans Administration were not

adequate to assist them in readjusting to their primary caregiving responsibility for their grandchildren. They discover that there is much bureaucratic red tape to be gotten through in order to access financial and health-care assistance for their grandchildren. The grandparents contact a child advocacy agency and learn about their rights and the rights of their grandchildren. They also learn what resources are available and take parenting classes to enable them to access these resources and to lobby their lawmakers for better child welfare programs. The husband and wife are acting as primary caregivers to their grandchildren, support to their divorced daughter, and advocates for their grandchildren and all children. This family has adapted to its changed circumstances by changing its structure, redefining its roles, and acquiring new skills. These deeper changes--changes in definitions and meanings, reduction of demands, or acquisition of new capabilities--are characteristic of the adaptation phase which is illustrated in Figure 4.

Situations may occur where families receive no clear guidelines or blueprints from the suprasystem and environment on how to adjust or adapt to their demands. Such situations are most likely to occur when changing social conditions no longer fit old norms. Difficulty can also occur when there is no clear definition of what a family is, boundaries between system levels become blurred, or discrepant meanings for behavior exist between family members. The grandparents in the vignette had not expected to be primary caregivers for a third generation of children and had to redefine their roles and expectations. Their friends also had to redefine their expectations of this couple; some friends found that they did not enjoy socializing with the couple when the grandchildren were around and distanced themselves. The schools the grandchildren attended as well as the child welfare agencies were not equipped to address the differences between the grandparents' circumstances and the more

traditional family. The grandparents were often confused by the issues discussed and vocabulary used by personnel working with the grandchildren.

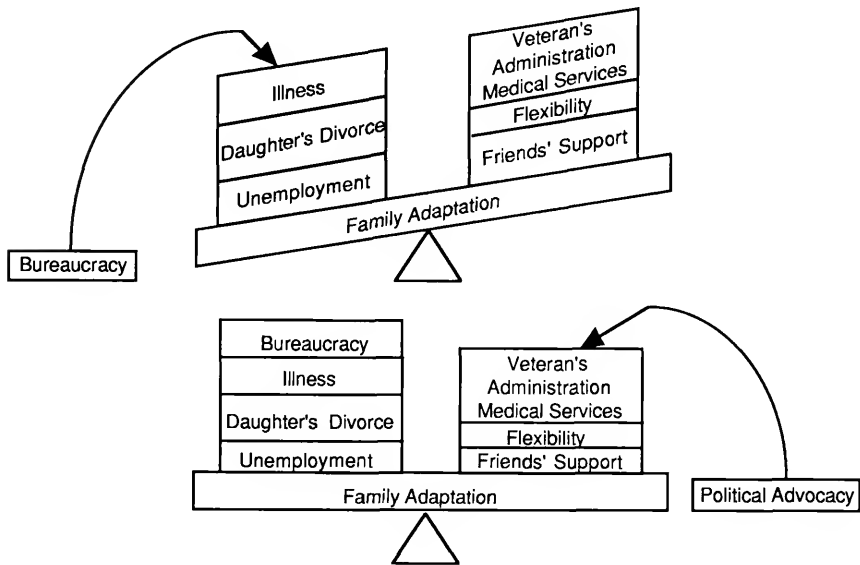


Figure 4. Adaptation

Their own failing health and tight finances impeded the grandparents' participation in many school activities as well as limited the grandchildren's participation. Grandparents who are raising young grandchildren with disabilities or at risk for disabilities may experience such difficulties. The changes grandparents who have primary responsibility for the care of their grandchildren experience at the subsystem, system, and suprasystem levels may not be addressed by the systems that traditionally assist families of children with disabilities.



## Analysis of the Relevant Literature

### Families of Children with Disabilities or At Risk

The FAAR Model's three critical factors of family adaptation (demands, capabilities, and the meaning ascribed to each) are used as the basis for the literature review of families of children with disabilities. First, demands reported by families of children with and without disabilities are presented. Second, families' perceptions of their capabilities are reviewed. Finally, families' sense of cohesion and adaptation is reported. By identifying the demands and capabilities parents who are raising children with disabilities experience as well as how they have adapted to these demands, service providers may begin to understand the issues and processes experienced by nonparent family members who are raising children with disabilities.

The data discussed in the following sections were derived from self-report instruments and interviews. In effect, the data report the meanings families ascribe to their demands and capabilities. Although divided into three categories, much of the data originated from the same investigations. The pertinent results are reported under the appropriate category. The sample populations of the studies that appear in more than one category are described in their initial review.

### Demands

Seven studies are reviewed regarding the demands experienced by families of children with disabilities. Demands were measured as parents' information-seeking interests, parents' problems, parents' attitudes, family time demands, family financial demands, family acceptance, problems locating services or with referral systems, the need for reasonable effort in times of crisis, problems with parent-professional collaboration, sources of stress, and problems planning for future services. The majority of the participating parents

were Caucasian, married, and within the middle socioeconomic range. The children of the parents participating in the investigations ranged in age from birth to 21 years. The children also varied in their diagnoses and the severity of their disabilities. Demands experienced by the participants were measured through interviews and/or participant completion of questionnaires. The results of these investigations can serve to make service providers more sensitive to the demands experienced by parents of children with disabilities. This information can be incorporated in the development, implementation, and evaluation of intervention programs for families and young children with disabilities. Additionally, the results of these investigations serve as a starting point for investigating the demands experienced by nonparent primary care providers of young children with disabilities or at risk for disabilities including grandparents and the factors that may affect those demands.

Literature review for demands. Bailey and Simeonsson (1988) surveyed 34 two-parent families participating in a home-based infant intervention program. The average age of the infants was 14 months, and they displayed a variety of disabilities. The majority of the respondents were Caucasian. Forty-eight percent were male and 52% were female. Half of the sample was lower socioeconomic status. The purpose of the study was to develop an instrument, the Family Needs Survey, for the direct assessment of family demands. The survey was used as part of a battery of assessment tools in a study of inservice training on family assessment and goals writing.

Results of the survey indicated that parents wanted information about how to teach their children, services that were currently available, and services that would be available in the future. Parents also wanted reading material about other parents of children with disabilities. Mothers requested more information about their children's disability, opportunities to meet other parents,

more time for themselves, and help in paying for basic expenses than did fathers. Parents expressed a desire for respite care for their children so that they may spend time alone with their spouse. Parents also reported feeling fatigue as well as guilt that their work took them away from their children. Stress associated with their in-laws and other extended family members was another need difficulty reported by parents. Parents also experienced concerns about their children's upcoming surgery. The most common general concern expressed by parents was concern about the future, particularly the future developmental and skill status of their children.

Gowen, Christy, and Sparling (1989) surveyed the informational needs of fathers and mothers of children, ages birth to 8 years, who were disabled or developmentally delayed. The sample population included 367 parents (267 mothers, 100 fathers), the majority of whom had one child. The majority of respondents were between 20 and 39 years of age, Caucasian, married, and middle class socioeconomic status. The majority of mothers were not employed outside the home. The respondents' children ranged in age from birth to 8 years. There were more male children than female. A questionnaire that measured their information-seeking interests and preferred sources of information was disseminated to and completed by the parents.

Gowen et al. (1989) noted that parents expressed a need for information regarding various aspects of child development and whether they could help their young children reach their full potential. Interest was also expressed by parents in learning how to deal with the emotional highs and lows of parenting children with special needs. Parents noted they had difficulty finding time for themselves, problems finding good baby-sitters, and a need for information about community resources. Additionally, parents expressed their concerns

regarding their children's legal rights and how to plan for the long-term needs of their special needs children.

McLinden (1990) described the impact of a young child with special needs on the way in which parents viewed various aspects of their daily lives. The participants included 48 mothers and 35 fathers of 48 children (27 boys and 21 girls, age 26 to 50 months) who had developmental disabilities. Each of the fathers and 41 of the mothers were married. The majority of the families were Caucasian with an income of \$30,000 or more. The average number of children in the families was two. Mothers and fathers each completed questionnaires that also measured family support, adaptability and cohesion, and functioning.

McLinden noted that mothers cited more problems than fathers. The problems mothers reported were multiple demands on their time especially by the children with special needs, difficulty accepting their children, a diminished sense of personal well-being, and limited social relationships. Fathers also reported problems with acceptance and time demands. Approximately 40% of the mothers reported problems with the disproportionate allotment of their time to their children, resulting in a lack of time for themselves or the rest of their family. Mothers also reported feeling fatigued. Fathers indicated that building the family schedule around the special needs of their children was problematic. Parents were also concerned about their children's future. Fathers had an additional concern for the amount of progress their children made.

Irwin (1992) investigated the information and referral needs of parents of children with disabilities, their need to establish an information and referral system on disabilities, and their use of sources to meet their information and referral needs. Seven parents of children with disabilities were interviewed. Each of these parents was asked to participate because he or she had

recognized a need for information and referral services and had worked toward developing such a system.

Parents expressed a critical need for accurate, specific, and current information over the lifetime of their children. Another need expressed by parents was the need for a range of sources because no one service met all their information and referral needs. Parents were frustrated with the lack of one central service point for information and referral.

Petr and Barney (1991) conducted a study to determine what is necessary to keep children with disabilities in their homes. The sample consisted of 39 parents of children (ages birth to 21 years) with developmental disabilities, emotional disabilities, or whose needs were supported with technology. Focus groups were employed to measure parents' opinions about their family needs, crises that have occurred, professional support, and a definition of reasonable efforts.

Parents reported a need for a variety of services including respite care, quality special education programs, and information about available programs. Parents also expressed the need for counseling for their children, themselves, and their family. According to these parents, the care system needs to (a) better reflect certain attitudes and values such as integration of children with disabilities into the mainstream community, (b) treat all children as children, and (c) avoid labels and generalizations. Other needs reported by families were the need for emotional support, being prepared to act as an advocate for the children and their families, and financial support to meet the costs of caring for their children. Despite family subsidies and Medicare waivers, many expenses incurred by families for their children remain uncovered.

Petr and Barney (1991) noted families' opinions regarding what constituted reasonable efforts in crisis situations. Stress specific to system-

induced crises that arise when someone outside the family intrudes into their family life or the lack of smoothness in the practices and policies of care systems were described by parents. General stress was also experienced by families due to a lack of adequate sleep, the daily grind of coping, and specific acute situations (physical illness, injury, family events) that impaired parents' ability to provide care.

Todis and Singer (1991) investigated the sources and methods of dealing with stress in families with adopted children with severe developmental or multiple disabilities. The sample included six middle class, Caucasian families with adopted children with severe disabilities. Semistructured interviews and participant observation conducted over 5 months measured sources of family stress, stress management strategies, and experiences with schools and helping agencies. The researchers also investigated the parents' decision to adopt one or more children with disabilities, plans for the future, positive aspects of parenting children with disabilities, and sources of instrumental and social support.

Sources of stress included medical crises and planning for medical procedures and the emotional upheaval experienced because of these crises and the children's status. The erratic behavior accompanying adolescence for typically developing children was an additional stress reported by the parents. An increase in stress was experienced when outside agencies became involved with the families. The greatest sources of stress for families were obtaining appropriate services from the various providers, determining eligibility criteria for various financial benefits, and compliance with those criteria. Stress was also experienced as a result of attempting to reconcile medical and educational recommendations with parents assessment of children's strengths and needs. Parents did not always agree with the professional's assessment of

their children's status and the recommendation made based upon that assessment.

Bailey, Blasco, and Simeonsson (1992) extended the research on parental adaptation to children with disabilities through a comparative analysis of the needs for services expressed by mothers and fathers. Four data sets were combined for this analysis: (a) a sample of 78 families enrolled in home-based infant intervention programs, (b) a sample of 20 parents whose children were enrolled in a university-based mainstreamed program for infants and preschoolers, (c) a sample of 139 parents served by an Early Intervention program, and (d) a sample of 185 families from a variety of Early Intervention programs. Participants represented families of diverse structure, geographic locations, socioeconomic status, and race. Children's ages ranged from 3 months to 14 years. A total sample of 422 families completed surveys measuring family needs related to information, support, explaining to others, community services, finances, and functioning.

The greatest need parents expressed was the need for information. Parents needed more information about their children's conditions or disabilities, how to teach their children, and present as well as future services their children might receive. At least 30% of the parents expressed a need for help with information on handling their children's behavior, growth, and development. Other parent needs included (a) meeting other parents of children with disabilities, (b) reading material about families of children like theirs, (c) finding more time for themselves, and (d) paying for basic expenses. A difference was noted between the expressed needs of mothers and fathers. Overall, mothers expressed significantly more needs than fathers.

Summary of demands. The results of the research on the demands experienced by families of children with special needs illustrate four primary

demands. Families perceived that they needed (a) accurate and current information regarding their children's present and future status, educational options, and other families' experiences raising children with disabilities, (b) respite care for their children so that they may have time to themselves or with other family members, (c) financial assistance to help meet the costs of raising children with special needs, and (d) long-term planning for the care and treatment of their children. Two factors were identified as affecting parental stress: parent gender and the involvement of outside agencies in the families lives.

In general, investigations of families' demands have not incorporated comparison groups of families of typically developing children. This approach does not label families of children with disabilities as dysfunctional or deficit. This allows researchers to focus not on the differences between families but on the families' perception of the demands they experience and using this information to develop interventions to alleviate those demands. However, researchers have focused primarily on white, two-parent families of middle socioeconomic status. We can also assume that two-parent, middle socioeconomic status families have capabilities with which to eliminate many demands that minority, single-parent, or other nonparent families as well as lower socioeconomic families may not possess. Although there may be a common core of demands experienced by families that are directly related to their children with disabilities, we cannot assume that the existing research is representative of all the demands experienced by nontraditional families. The next step in family research is to determine the demands experienced by nontraditional families and factors that mediate these demands. It may be that demands such as the need for information, respite care, financial assistance, and long-term planning are more acute for nontraditional families, especially



grandparents, raising children with disabilities and at risk for disabilities. Such information can assist service providers in developing intervention programs for children and families. The capabilities families use to meet these demands are also of interest to family researchers and professionals working with children with disabilities and their families. In the following section I review eight studies investigating the capabilities of families of children with disabilities.

#### Capabilities of families of children with disabilities or at risk

The second critical factor of the FAAR Model is families' capabilities to balance the demands they experience. Families' capabilities and the meaning families ascribe to them play an important role in the families' adjustment or adaptation to their life situation. Participants in some of the following investigations compared families of children with disabilities with families of typically developing children. The children of the participants ranged in ages from birth to 21 years. The children also varied in their diagnoses and the severity of their disabilities. The study by Brown (1990) is significant in that single parents were included in the sample population; all other studies focus on what is perceived as the traditional family structure. The study by Paez (1992) is also noteworthy in that it included African-American and Hispanic families as well as Caucasian families. The investigators of the following eight studies measured capabilities as support networks, support systems, family strengths, internal resources, coping, and stress management. Capabilities were measured through self-report questionnaires (completed by the participants) and/or interviews with the participants. Therefore, these studies present the families' ascribed meanings (the third critical factor of the FAAR Model) as well as their identification of the capabilities they access to balance their demands. Identifying parents' capabilities and their mediating factors may

assist researchers in understanding why some families adapt more readily to children with disabilities than other families.

Literature review for capabilities. Kazak and Marvin (1984) described some of the differences between families of children with disabilities and families of typically developing children. The study was one component of a larger study of family stress and social support networks in families of children with disabilities. Fifty-six families of children with a major diagnosis of spina bifida were compared to 53 families of typically developing children. The families participating in the study were matched for age of child. Families were interviewed and asked to complete a packet containing a parenting stress index and adjustment scale.

The social support networks of parents of children with disabilities were significantly smaller than those of the comparison group. However, there were major group differences in friendship networks. Members of the friendship networks of families of children with disabilities were more likely to know each other and interact with each other. Therefore, parents of children with disabilities belonged to more of the same networks than did families of children without disabilities. This explains the smaller, and denser, social support networks of parents of children with disabilities. No major differences were found between the two groups in size of their family networks (nuclear and extended family members).

Dyson and Fewell (1988) compared stress and adaptation in families of children with disabilities and in families of typically developing children. The mean age of the children in the sample was 4.7 years. The children had diagnoses of vision impairment, hearing impairment, physical impairment, social retardation, language impairment, mental retardation, or behavior disorder. The participants represented middle socioeconomic status,

two-parent families. Thirty families, 15 with children with disabilities and 15 with typically developing children, completed a packet of questionnaires. The questionnaires measured the impact of a family member with a disability or chronic illness on the family. The family's emotional responses were also measured. Mothers were investigated as to their degree of pleasure in their children and satisfaction with the parenting role. Mothers' satisfaction with their intimate relationships was also measured. Other measures included available social support (from family and friends) and community support (from neighbors and formal institutions). The number of potential sources of social support and the degree to which they have been helpful to families raising a young child were also investigated.

There was no significant difference between groups on parenting or social support scales. However, parents of children with disabilities had more professional helpers, program help, and neighbor help. Families with more support experienced less stress. An increase in social support was associated with a decrease in the level of stress parents experienced.

Naseef (1989) added to the body of literature dealing with successful adaptation and coping of families of children with disabilities. The 13 parents who made up the sample were identified by professionals in the children's educational setting as coping successfully without undue behavior problems. Each family also contained one nondisabled child of elementary school age or beyond. Three interviews were conducted with each family, one with the parents, another with the siblings, and the third with the children with disabilities. Interviews focused on the families' efforts to adapt to stress over time as well as resources and perceptual factors used by the family to develop new coping mechanisms designed to achieve and maintain family balance.

Parents relied heavily on their marital relationship as a source of support. Another source of support was other parents of children with disabilities. Parents reported that a key factor in coping successfully was maintaining family unity and stability. Naseef concluded that families who are functioning well are families whose members communicate with each other and freely question and discuss issues concerning their disabled siblings.

Brown (1990) investigated the perceptions of parents of preschool children with and without disabilities regarding the impact their children had on parenting stress, family strengths, family support, and contributions to family functioning. Differences between the two groups regarding the impact of the children on their families were also investigated. Information was collected via surveys from 91 parents of children with disabilities, ages birth to 5 years, and 79 parents of children without disabilities, ages birth to 5 years.

A statistically significant difference between the perceptions of the two groups was reported regarding the impact of their children on family strengths. Parents of children with disabilities perceived their families as having fewer family strengths and experiencing more parenting stress than parents of typically developing children. Single parents of children with disabilities perceived themselves as experiencing more stress than their married cohorts. However, a larger percentage of single parents of children with disabilities perceived their families as having more strength than single parents of typically developing children. There were no significant differences between the family groups on perceived helpfulness of various supports needed to raise young children. However, single parents in general perceived less helpfulness from various supports than did married parents. Brown concluded that on many important dimensions parents of preschool children with and without disabilities are more alike than different.

In the McLinden (1990) study, no statistically significant differences were noted between mothers and fathers of children with disabilities. Parents' perceptions of the availability and helpfulness of sources of support did not differ. Parents also had similar perceptions of their current family functioning and their perceptions of the ideal family functioning.

Petr and Barney, in their 1991 study, also reported that families who kept their children with disabilities in their home listed their family, church, and friends as important support systems. An additional source of support was other parents of children with similar disabilities.

In their study of adoptive families, Todis and Singer (1991) noted that families who had adopted children with disabilities managed stress through a number of strategies. Parents reported that they used time away from the family as one means of coping. Parents incorporated household management techniques as well as routine medical and hygiene management to help manage stress. Contact with other families of an adopted child with disabilities and involvement with their church were additional methods of stress management. Families found that focusing on positive aspects of their families and an absence of parental guilt associated with their children's disabilities assisted them in coping with their daily stress. Families reported that feelings of mastery or control over their problems and evidence of improvement in the physical and mental health of their adopted children further enhanced their stress management.

Paez (1992) examined the functioning of families of children with a mental handicap. Members of 171 families participated in her investigation. The racial representation of the participants was 61% Caucasian, 29% African-American, and 10% Hispanic. Mothers made up 88% of the sample while 11% were fathers. The mean age range of the parents was 25 to 44 years. The

mean age of the children was 9.11 years. Daughters made up 42% of the children and 58% were sons. The degree of disability for the children was 56% Educable Mentally Handicapped, 31% Trainable Mentally Handicapped, and 13% Severe/Profound Mentally Handicapped. Families' perceptions of their internal resources and coping strategies were measured.

Paez noted that families with younger children reported more intrafamily qualities or characteristics that families could mobilize, for example, a sense of competence. More internal resources were also reported by families with more financial resources. Older parents reported more internal resources. The intrafamily qualities of Hispanic families was lower than either Caucasian or African-American families. Children's gender and severity of disability were not significantly related to the reported internal resources of the families. Stressors faced by the families within the past years also were not related to the families' internal resources. However, families reporting more life stressors in the past years tended to employ fewer coping strategies. Families of children with severe and profound mental disabilities also reported fewer coping strategies.

Summary of capabilities. Researchers have found that families of children with disabilities have smaller and denser friendship networks but larger social support systems in terms of professional helpers. Families did not differ significantly in their family support systems, that is, parental, spousal, and other familial support. However, support available to single parents differed from those of married parents. Although single parents with children with disabilities perceived their families to be stronger than other single parents, single parents in general reported their support networks to be less helpful. Hispanic families had fewer internal familial capabilities. Overall families with more financial resources had more internal capabilities with which to balance their demands. The results of these studies indicate that family structure, as well as

socioeconomic status and ethnicity, affects the capabilities families identify and access. The information garnered from these investigations begins to provide insight into the capabilities of nontraditional families. One would expect families that represent disenfranchised groups to experience fewer capabilities.

However, the extent to which the capabilities of nontraditional families are limited as well the capabilities they do access remains unclear and requires further investigation. Working with families to identify their capabilities and the factors which affect these capabilities is one step in the process of balancing demands and capabilities and adapting to new experiences. Understanding how families adapt to the experiences of raising children with disabilities can be beneficial to families and service providers as they plan and implement intervention services. In the following section, I review 17 studies of family adaptation.

#### Adaptation of families of children with disabilities or at risk

According to the FAAR Model, the three critical factors of demands, capabilities, and ascribed meaning interact to affect families' adaptation. The investigators whose works are reviewed in this section studied the effect families' needs and capabilities have on their satisfaction, coping, and other indicators of adaptation. Family adaptation was measured through a variety of dependent variables. Parent attitudes, satisfaction, adjustment, and parenting behaviors were included as measures of adaptation. Other outcomes were familial adaptation, life satisfaction, family harmony, family functioning, and marital satisfaction. Emotional distress and personal stress were also measured.

As in the family research reviewed in previous sections, the majority of the participants represented the traditional American family, that is, Caucasian, two-parent, middle socioeconomic status. Exceptions are Paez' (1992) study

investigating Caucasian, African-American, and Hispanic families and the Schilling, Kirkham, Snow, and Schinke (1986) report on single mothers of children with developmental disabilities. Some of the investigations included families with typically developing children as a comparison group. Again, the children of the participants varied in diagnoses and severity of disabilities as well as ages. The majority of the studies incorporated self-report questionnaires and/or interviews, providing the parents' perspective of their families experiences and adaptation to these experiences. The following studies provide insight into the processes and experiences of families raising children with disabilities.

Literature review of adaptation. Crnic, Greenberg, Ragozin, Robinson, and Basham (1983) examined the effect of stress and various types of social support on maternal attitudes and mother-infant behavior with groups of premature and full-term infants. One hundred five mother-infant pairs (52 were premature and 53 were full-term) made up the sample. None of the infants had gross neurological or physical impairment, and groups were matched for family ethnicity and mothers' level of education. This 2-year longitudinal study consisted of home interviews measuring the mothers' life stress, social support, general life satisfaction, and satisfaction with parenting.

There were no significant group differences between the premature and full-term mother-infant groups. The mothers' perception of their social supports and life stress significantly predicted their general life satisfaction. Mothers who perceived that they had greater support were more satisfied with their lives as were mothers who perceived that they had less stress. Mothers who perceived their circumstances to have high stress and low support were the least satisfied with their lives.



Mothers' attitudes towards parenting were significantly predicted by their intimate (spouse and immediate family) and friendship support systems. Another strong predictor of mothers' parenting attitudes was community support. Mothers with greater support from intimates, friends, and community and less stress reported more pleasure in their children and in the parenting role. Stress was significantly related to maternal behavior predicting mothers' sensitivity to their infants' cues. Mothers who are sensitive to their infants' cues are able to understand infants' gestures of acceptance, need, or rejection and are better able to meet the needs of their infants. Such mothers are also more likely to perceive positive reinforcement from their infants, which helps to reduce the stress and increase the pleasure associated with caring for an infant. Indeed, mothers experiencing greater stress were rated as less sensitive to their infants' cues.

Mancoske (1983) compared the attitudes of parents of children with disabilities to those of a control group of parents. Seventy-three parents of children with disabilities and a control group of 98 parents completed a survey measuring family attitudes toward persons with disabilities, family environment, and child behavior. The attitudes of the two groups were not significantly different except parents of children with disabilities felt that their children had more behavior problems. These parents also felt more intensely about their children's behavior problems.

In their 1984 study comparing families of children with disabilities and families of typically developing children, Kazak and Marvin reported that as a parental unit, families of children with disabilities experienced higher levels of parenting stress. Mothers of children with disabilities experienced the highest level of stress, followed by fathers of children with disabilities, mothers of children without disabilities, and finally fathers of children without disabilities.

Mothers of children with disabilities perceived their children as less adequately fulfilling the mothers' own expectations for their children. This incongruence may explain why these mothers experienced more depression associated with issues of parenting and felt less competent as mothers. Mothers spent a significantly greater amount of time caring for their children at bedtime while having a significantly smaller percentage of time for themselves or their spouses. Mothers of children with disabilities also spent a significantly larger portion of their leisure time with extended family than did mothers of typically developing children. Fathers, in general, did not differ in the total amount of time they spent caring for their children. However, fathers of children with disabilities did spend significantly less time caring for their children at bedtime.

Mothers and fathers of both groups were not significantly different in their total marital satisfaction. Actually, parents of children with disabilities experienced somewhat higher levels of marital satisfaction. However, there were differences in specific aspects of marital satisfaction. For example, fathers of children with disabilities reported significantly higher levels of disagreement with their spouses over how and when to discipline their children.

Schilling, Kirkham, Snow, and Schinke (1986) conducted an investigation to determine how single mothers of children with developmental disabilities appraised their circumstances. Forty-eight single (never married, divorced, separated, or widowed) mothers and 48 married (living with legal spouse) mothers completed individually administered questionnaires. All mothers had full-time custody of their children. Children's ages ranged from 2 to 10 years. Mothers' ages ranged from 21 to 43 years.

Parental and familial adaptation to children with disabilities or chronic illness were measured. Other outcomes measured included current and desired family-related interactions and responsibility and satisfaction with family

life. More single mothers felt they had often given up things they really wanted to do in order to care for their children than did married mothers. Although the total family functioning did not differ between groups, there were individual item differences. For example, single mothers spent less time with their other children, less time in leisure, and missed more work than did married mothers. Single mothers indicated that their work should not be disrupted, and there should be more interactions with their relatives. This may reflect their need for job and financial security as well as other types of social support. A discrepancy also existed between single mothers' perceptions of their current functioning and their desired level of leisure time and support from relatives and friends. Single mothers who received social support and were able to enjoy leisure time perceived themselves as better able to function.

Mothers did not differ on the total quality of life but did differ on individual items. Single mothers were less satisfied with their families, number of children, relationships with relatives, and their own health. Single mothers needed more space for their own needs and their families' needs. Single mothers were also less satisfied with their education, occupation, job security, income, money for future needs, and neighborhood. The association between family functioning and quality of life appears evident. Many of the issues raised as stressors for single mothers appeared in both measures, that is, social support, leisure time, and job and financial security.

Dyson (1987) evaluated parental stress, family functioning, and social support to determine the relationship between parental stress and family functioning in families of children with disabilities. One hundred ten families were equally divided into two groups: families of children with developmental disabilities and families of typically developing children. All children were under 7 years of age. The families were matched for socioeconomic status and

family structure. Participants represented Caucasian, two-parent, middle socioeconomic status families. The mean age of the mothers was 34 years and 36 years for the fathers.

Families were asked to complete a packet of survey questionnaires and scales. The impact of a person with developmental disabilities or chronic illness on other family members was measured. Data were collected on the characteristics of the families' social environments. Information was also collected regarding the degree of helpfulness of different sources of support to families raising young children.

There was no significant difference between the two groups regarding family social environment. There was a significant difference between parental stress, family support, and family relationship. Although their parents and relatives were more supportive, families of children with disabilities reported higher levels of stress. Young children with disabilities induced greater stress in parents than did typically developing young children. Greater parent and family problems were incurred by the care of children with disabilities. Parents of children with disabilities were more pessimistic about their children's future, present behavior, and physical characteristics. Families of children with disabilities also rated significantly higher on the emphasis they placed on achievement, religious beliefs, and the use of rules and control as a method of operating family life. However, families of children with disabilities were not unlike other families in their general functioning and availability of social supports.

Kazak (1987) reported data representing portions of larger studies on stress and coping. The data were investigated to determine (a) if families of children with disabilities evidence higher levels of personal stress and lower levels of marital satisfaction than matched comparison families, (b) if social

networks of families of children with disabilities are smaller and more dense than those of comparison groups, and (c) the differences among three groups of families of children with disabilities. The three samples consisted of two-parent families carefully matched for child age, geographic locale, and income. One hundred twenty-five families had children with disabilities, and 127 families had children with no disabilities or psychological conditions. The first sample consisted of 36 families with institutionalized children with mental disabilities and 33 families with typically developing children. The age of the children with disabilities ranged from 9 to 30 years. Forty-three families of children with phenylketonuria (PKU) and 47 matched families of children with no chronic or psychological problems made up the second sample. The ages for the children were 1 to 8 years. The third sample consisted of 46 families of children with spina bifida and 47 families of matched typically developing children. The children's ages were 1 to 6 years.

Families completed a social network interview and questionnaire which measured families' anxiety, depression, marital satisfaction, and network size. No differences were found between groups regarding marital satisfaction although there were differences in levels of stress parents experienced. Mothers of children with disabilities experienced significantly higher levels of personal stress. Fathers, in general, reported lower levels of stress than did mothers. Families of children with disabilities were not more isolated although there were differences in (a) their total network size (social support networks of parents of children with disabilities were significantly smaller but family networks did not differ in size), (b) density of their social network (members of the networks of families of children with disabilities were more likely to know each other and interact with each other), and (c) the size of fathers' friendship network.

Bristol, Gallagher, and Schopler (1988) conducted an investigation to determine if depression, marital adjustment, and observed parenting varied with gender of parents and young sons' status (disabled or nondisabled). Parents' gender and sons' status were also investigated in terms of affect on specific types of instrumental and expressive spousal support. The relationship between sons' status and specific characteristics of young sons to differences in the level of the fathers' involvement was also investigated. The relative contribution of sons' status, current levels of instrumental and expressive support, and disharmony between current and appropriate spousal support to perceived adaptation and observed parenting was explored for both mothers and fathers of young boys with disabilities and typical development.

The sample consisted of 56 two-parent families (31 with boys with developmental disabilities and 25 with typically developing boys). The boys with developmental disabilities, ages 2 to 6 years, were recruited from a free statewide program for children with autism and severe communication disorders. The sample consisted of Caucasian, male children from intact biological families. Participating families were group matched for age, gender, and family demographics.

Mothers and fathers completed surveys and participated in in-home assessments. Measures of parents' psychological distress and ability to adapt to children in the home were collected. Other outcomes included marital adjustment, disruption of family routines, and spousal instrumental and expressive support. The majority of the parents in both groups were not at risk for depression. Although not statistically significant, twice as many mothers of sons with disabilities were at risk for depression. Mothers in general reported a significantly greater number of depressive symptoms.

Although parents of sons with disabilities reported more marital adjustment problems, the majority of parents were not at risk for marital problems. However, a significantly greater proportion of fathers of sons with disabilities were at risk for significant marital problems. This may be associated with the division of labor in families with sons who are disabled and the degree of disruption in their lives. Fathers in these families assumed significantly less responsibility for general household tasks and were less involved in the care of their sons, especially sons with more severely atypical language, affect, and behavior. Families of sons with developmental disabilities reported mothers as being primarily responsible for child-care chores with fathers providing some assistance. These mothers also received less recreational support from their spouses. The division of labor was different in families of typically developing sons where responsibility for child care was reported as divided almost equally between both parents, although mothers in both groups reported receiving less emotional support from their husbands. Fathers did not report the same discrepancy in the emotional support received from their wives. Finally, parents of sons with developmental disabilities reported more disruptions in their daily lives and experienced difficulty in adapting normal parenting skills to their sons' special needs.

Cook (1988) investigated whether mothers experience a disproportionate amount of emotional distress when compared to fathers in families residing with children who are chronically mentally ill. Measures of stress, anxiety, resentment, grief, depression, fear, emotional drain, hopelessness, and anger were collected through home observations and interviews. The sample consisted of 36 families who were clients of a large urban psychiatric rehabilitation agency. The families were composed of 13 sets of mother-father couples, 20 individual mothers, and 3 individual fathers. The

parents resided with their children at the time of their children's entry into the program. The majority of parents were employed and had other children. Parents' mean age was 57 years. Sixty-six percent of the children with chronic mental illness were male. Approximately half of the children were in their 20s, had been hospitalized at least twice, and their illness had lasted for 2 or more years.

Parents most frequently reported feelings of stress and anxiety. Parents also experienced grief, hopelessness, and feeling drained. Fathers, however, indicated a greater severity of hopelessness. Mothers' feelings of stress, anxiety, resentment, grief, depression, fear, emotional drain, and anger were more intense.

Dyson and Fewell (1988) compared stress and adaptation in families of children with disabilities and in families of typically developing children. Thirty families, 15 with children with disabilities and 15 with typically developing children, completed a packet of questionnaires. The mean age of the children in the sample was 4.7 years. The sample represented middle socioeconomic status, two-parent families.

The questionnaires measured the impact of family members with disabilities or illness on the family and the families' emotional responses. Other measures included mothers' degree of pleasure in their children and satisfaction with their parenting role. The available social support and mothers' satisfaction with intimate relationships and community support as well as the number of potential sources of social support and the degree to which they have been helpful to families raising young children were also investigated.

Mothers in general and parents of children with disabilities had significantly higher levels of stress. There was a significant difference between the two groups of parents on pessimism, child characteristics, and physical



incapacitation. Parents of children with disabilities rated higher on each of these.

Parents of preschool-aged children with disabilities, in comparison to parents of typically developing children of the same age, experienced more stress. This stress came from four sources: (a) children's characteristics, (b) physical incapacitation, (c) parental pessimism in relation to their children, and (d) the severity of children's disabilities. Parental stress mounted with children's behavior or attitudinal deficiency as well as children's other limitations due to physical incapacitation. However, both groups of parents enjoyed their parenting role to the same degree. Parents' level of stress decreased as their level of social support increased. Parents of children with disabilities had more outside support from professional service providers, programs, and neighbors.

Frey, Fewell, and Vadasy (1989) conducted a longitudinal study examining the relationship of parent-child characteristics and competencies, the supports available to the family, and how these factors influence parent and child outcomes. The participants were 48 mothers and 48 fathers of young children with disabilities. The mean age was 35 years for the mothers, 37 years for the fathers, and 59 months for the children. The families were all intact with an average of two children. A battery of questionnaires was completed by the participants.

The questionnaires measured parental adjustment to their children and family and personal adjustment. Results from the first year indicated that children's communication skills are important predictors of parents' adjustment. The better the children were able to communicate, the higher the parents' level of adjustment. Overall, parents of children with higher ability levels consistently reported higher levels of adjustment to their children as well as family and personal adjustment. Although mothers of girls had a better overall adjustment,

mothers' personal adjustments were also predicted by their level of social support. Social support also predicted fathers' family and personal adjustment. Fathers' total adjustment was related to their problem solving ability. Religious beliefs were not predictive of parental adjustment.

Frey, Greenberg, and Fewell (1989) examined the relationship of child characteristics, family social network, parent belief systems, and coping styles to parents' responses to their specific children. The quality of general family interaction and parent's psychological functioning were also investigated. Forty-eight mothers and 48 fathers of young children with disabilities participated in the study. Mothers' mean age was 37 years, fathers' mean age was 39, and children's mean age was 6.9 years. All families were intact with an average of two children. Mothers and fathers, separately, completed questionnaires. Mother also served as informant to interviewers assessing communication, daily living skills, socialization and motor skills of their children with disabilities. Data were also collected through structured-question format interviews with both parents jointly.

Parents experienced greater parenting stress with boys and children whose communication skills were low. The parents' social network was not related to parent stress but was related to family adjustment. The important component of social networks varied for mothers and fathers. For example, the family adjustment of mothers was better if the level of their social support was higher but was not related to the level of criticism they received. On the other hand, fathers' family adjustment was better if their level of criticism was low but was not related to their level of social support. Parents' psychological distress was significantly related to the percentage of their coping strategies that were specifically devoted to problem-focused coping and seeking of social support. The higher the level of coping strategies parents used, the lower the level of

their distress. However, the most powerful correlate of parent outcomes was parental belief. For example, the mothers' positive belief system buffered their psychological distress. Frey, Greenberg, and Fewell concluded that social network and family adjustment reflected an interaction pattern and were strongly related.

Austin (1990) described demographic, seizure, and family characteristics associated with good and poor adaptation to childhood epilepsy and contrasted them with demographic, asthma, and family characteristics associated with good and poor adaptation to childhood asthma. The participants included 254 children, their mothers, and their current school teachers. The children (128 with epilepsy, 126 with asthma) ranged in age from 8 to 12 years. Participants were asked to complete surveys measuring family demands, adaptive resources, coping, adaptation, and child adaptation. Results for the group with epilepsy indicated that younger children and children with more seizures adapted less well. Children, in both groups, who were less well adapted were associated with families experiencing significantly more demands or stressors or with lower levels of family resources. Austin concluded that family variables, especially the mother's attitude, are associated with child adaptation to both epilepsy and asthma.

Brown's (1990) investigation of the perceptions of parents of preschool children with and without disabilities yielded parenting stress scores for both groups within the normal range. There were, however, statistically significant differences between the two groups regarding the impact of their child on parenting stress. Parents of children with disabilities perceived themselves as experiencing more parenting stress. Single parents of preschoolers with disabilities experienced more stress than did their married counterparts.

In the McLinden (1990) study discussed earlier, mothers of children with disabilities cited more problems than fathers did in family adaptability, cohesion, and functioning. The problems mothers reported included difficulties in their acceptance of their children, in their sense of well-being, and with their social relationships. Fathers also reported problems with acceptance. There were no statistically significant differences on perceptions of current family functions and perceptions of ideal family functioning between mothers and fathers.

Park (1990) investigated the relationship between stress experienced by parents of children with multiple disabilities living at home and a series of eight parent, child, and family characteristics. Measures of stress due to life span care, cognitive impairment, child characteristics, family disharmony, pessimism, physical limitation, and finances were collected. High levels of stress were experienced by the parents. Total family stress was significantly related to both the degree of impaired mobility and mental retardation of the children. The greater the level of impaired mobility or the severity of mental retardation, the higher the degree of family stress. Impaired mobility was the most significant source of stress for parents who live with children with multiply disabilities. Park's findings support parents' need for respite care, psychological counseling, and financial assistance.

Beckman (1991) compared mothers and fathers of children with and without disabilities with respect to the amount of stress, caregiving requirements, and social support they experienced. The participants were 54 mothers and 54 fathers. Twenty-seven of the children were disabled and 27 were typically developing. Families were from the same geographic area and all were intact (two parents). The two groups were matched with respect to children's gender (15 males and 12 females) and age (18 to 72 months). The

majority of the families were Caucasian, representing a full range of socioeconomic levels with a tendency towards middle class.

Families were interviewed for child, parent, and general life stress. Informal (family, friends, neighbors) and formal support systems (professional service providers, programs) and caregiving requirements were also studied. Parents of children with disabilities indicated more stress across all domains than did parents of children without disabilities. Mothers indicated more stress than fathers. Mothers experienced more depression, difficulties with their sense of competence, and restrictions on their parental role. Mothers also reported more effects on their relationship with their spouse and on their health. There was a relatively high correlation between caregiving demand and mothers' stress. The total caregiving requirements were not associated with fathers' stress. Although children's age was not significantly associated with the amount of stress reported by parents, fathers' amount of caregiving requirements was significantly associated with the child's age. (In general, fathers tend not to be involved in the caregiving requirements of younger children and become more involved as their children age.) Fathers experienced more problems with attachment to their children. Despite increased levels of stress, parents in both groups reported similar degrees of attachment toward their children, acceptability of their children, and reinforcement from their children.

Parents perceived their informal support systems were more significantly associated with lower levels of stress in the parent and child domain than were formal support systems. Fathers reported formal support systems as a more useful way of mediating general life stress.

Dyson (1991) examined the presence of children with disabilities in association with parental stress and lower family functioning. The study

controlled for the mediating factor of socioeconomic status. The participants were parents representing 110 families, half with children with developmental delays or disabilities and half with children who were typically developing. Children were matched for age (under 7 years.). The majority of families were Caucasian, two parents, middle class, with at least two children. All families were requested to complete a packet of questionnaires and assessment scales measuring parental stress, family structure, family functioning, and family communication style.

Family stress was related to the care of children with special needs in middle socioeconomic status families. Families of children with developmental delays or disabilities scored higher in parental stress, achievement orientation (emphasis placed on achievement), moral-religious emphasis (emphasis on religious beliefs), and control (use of rules and control as a method of operating family life). Family groups did not differ in general family functioning. Dyson concluded that family stress need not lead to family dysfunction.

In her 1992 study of family functioning, Paez noted that more characteristics identified as maintaining effective family functioning were reported by Caucasian parents than either African-American or Hispanic parents. In general, parents perceiving their families as possessing more intrafamily qualities, such as a sense of competence, rated their families higher on effective family functioning.

Summary of adaptation. The studies reviewed in this section are investigations of families' adaptation to children with disabilities and the factors which affect their adaptation. Results of the studies are mixed. Although there do not appear to be significant differences between families of children with and without disabilities in overall stress, marital satisfaction, and parenting satisfaction, there do appear to be differences in individual characteristics of

stress and satisfaction. In general, mothers of children with disabilities experience more stress than do other parents. Fathers of children with disabilities experience more difficulty accepting and caring for their children. Single parents experience more stress than do their married counterparts. Parents of children with more involved disabilities, especially communication disorders, experience more stress than do parents of children with milder involvements. It would appear that parenting children with disabilities involves greater difficulty in some areas of coping or adaptation than parenting of typically developing children. The results of the studies reviewed regarding family adaptation indicate that nontraditional families--single parents, lower socioeconomic status, non-Caucasian ethnicity--experience greater difficulty adapting to their children's special needs. Further investigation is required investigating the adaptability of families with children with disabilities, especially nontraditional families. Investigators should be sensitive to the diversity of family structures and circumstances and use caution when generalizing across family types and populations, especially the family headed by grandparents who are raising young grandchildren with special needs.

#### Summary of families of children with disabilities or at risk

Results of the studies reviewed in the previous sections provide important information regarding the interactions between families' demands and capabilities and their effect on families' adaptation, especially to their children with disabilities. The studies reviewed also provide information regarding factors which mediate families' perceptions of their demands, capabilities, and adaptation. Although families of children with disabilities are more alike than different from families of typically developing children, there are differences. Families of children with disabilities expressed a common core of demands. First, families of children with disabilities reported their needs for

accurate and current information regarding their children's present and future. Parents also requested information and assistance in long-term planning for their children. Second, families reported their need for respite, enabling them to spend time alone or with other family members without the demands of caring for their children's special needs. Third, parents expressed a need for financial assistance in meeting the needs of their children as well as the demands of caring for their children. Factors which were identified as mediating the demands parents experience include gender and intrusion of an agency from outside the family.

Parents described a variety of capabilities used to meet and balance their demands. In general, parents of children with disabilities were similar to parents of typically developing children in terms of their support systems. Researchers noted that parents of children with disabilities lacked some of the capabilities that parents of typically developing children use. For example, although all parents reported similar family support systems, parents of children with disabilities have smaller, denser friendship networks and larger social support systems, especially formal supports. Some information is available on alternative family structures. For example, single parents with children with disabilities perceived their families to be stronger than other single parents. This may be due to the professional help they receive from service providers and programs. Single mothers, in general, noted differences in their support systems in comparison to two-parent families. Single mothers may feel more isolated from their friends and community than do married parents. Some information is also available on ethnic minority families. Hispanic families, for example, had fewer internal familial capabilities, such as a sense of competence, with which to meet their demands and adapt to their families' experiences.



The research on family adaptation indicates that there are not significant differences between families of children with and without disabilities. However, there do appear to be differences in individual characteristics of stress and satisfaction. For example, mothers of children with disabilities experience more stress while fathers of children with disabilities experience more difficulty accepting and caring for their children. The stress experienced by parents of children with more involved disabilities is also greater. It would appear that parenting children with disabilities involves greater difficulty in some areas of coping or adaptation than parenting of typically developing children. This may be especially true for nontraditional families. Single parents reported experiencing more stress than did married parents. Parents of boys experienced greater parenting stress, and Caucasian parents reported more characteristics identified as maintaining effective family functioning than did minority parents.

Based upon the limited information regarding the demands, capabilities, and adaptation of nontraditional family types, it would appear that they have fewer capabilities and greater difficulty adapting to their family situation. One would assume that the nontraditional family also experiences greater demands, or different demands, than the traditional family. However, this is still speculation due to the exclusion of alternative family structures and diverse socioeconomic and cultural populations from family research. The majority of research investigating families with children who are disabled has focused on Caucasian, middle class, intact families which limits the degree of confidence with which we can generalize the results to alternative family types.

According to the FAAR Model, families' demands and capabilities influence their adaptation to their alternative family structure. Educators and other service providers cannot assume the demands, capabilities, and

adaptations of nontraditional families; specifically, grandparents raising young grandchildren with disabilities are the same as those of the more traditional family. Indeed, the limited number of studies including diverse populations indicates that they are not the same. Research of families representing the diversity of cultural groups and structures found in our society is necessary if intervention programs are to be effective and efficient.

### The Changing Family

In order to be applicable to today's society, researchers will have to reflect the changing demographics of American society in their sample populations. According to Zakariya (1985), trends in the demographic data of the U.S. population suggested that in the year 2000, more students in American schools will be minorities, have mothers who work, or come from nontraditional and smaller families. As of 1988, about 60% of the children in the U.S. were living with both biological parents, a 7% decline since 1981 (Limoge & Dickin, 1992). The remaining 25% of the children were living in single-parent families; 11% were living in reconstituted families; and 4% did not live with either biological parent.

### Literature review of the changing family

Limoge and Dickin (1992) also noted that the 1990 U.S. Census documented that 73% of children younger than 18 years of age live with two parents (either biological, step, or adopted). It has been estimated that 15% of these families are step-families. Twenty-five percent of the children under 18 years of age live with a single parent. This is double the percentage of two decades ago. Over 30% of cohabiting households include children under the age of 15 years. There are an estimated 8 to 10 million children being raised in gay and lesbian headed households.

Currently, an estimated 3.2 million children in the U.S. and 260,000 children in Florida live with their grandparents or other relatives. This represents a national increase of 40% since 1980. In approximately 33% of these households neither parent is present, and grandparents assume the role of primary caregiver to their grandchildren (Brokaw, 1993; Brooks, 1994).

#### Summary of the changing family

The demographic trends indicate that the traditional family of two biological parents, middle socioeconomic status households are changing. Yet, these are the families on which family research has focused. This research is used in developing content for personnel preparation curriculum and service programs. This incongruence between the research and realities of family services limits the effectiveness of such programs. Service programs developed around this family model may fail to address the unique demands, capabilities, and adaptations of the new American families which are diverse in culture, ethnicity, socioeconomic status, and family structure. This is evident in the growing number of grandparents acting as primary caregivers whose grandchildren receive services from our programs. The literature on custodial grandparents indicates that their demands and capabilities, as well as some mediating factors, differ from those of the traditional family.

#### Custodial Grandparents

In this section I have reviewed five studies investigating grandparents who are primary caregivers for grandchildren. According to the FAAR Model, a crisis transitions families from adjustment to the deeper changes of adaptation. Grandparents who become custodial caregivers of their grandchildren may experience such a crisis. Early childhood special educators and other service providers will be working with this population and need to understand the demands and capabilities custodial grandparents perceive as affecting their

families as well as the adaptive characteristics of the new family. Few investigators have researched custodial grandparents, but their findings indicate differences between custodial parents' and grandparents' needs and capabilities.

#### Literature review of custodial grandparents

Shore (1991) and Shore and Hayslip (Focus on Research, 1993a) investigated a model of psychological functioning of grandparents raising grandchildren. The well-being, satisfaction with grandparenting, meaning of grandparenthood, and perceived relationships of grandparents with their grandchildren were measured. Participants in this study were 203 grandparents, 100 traditional grandparents and 103 who were custodial caregivers of their grandchildren. Custodial grandparents tended to be slightly younger and have a lower income than traditional grandparents. Grandparents completed a questionnaire examining their demographics, social resources and networks, and psychological functioning.

Grandparents acting as custodial caregivers reported less satisfaction with being a grandparent. Forty percent of the grandparents reported feeling isolated from their friends because of parenting responsibilities. Caregiving grandparents were three times as likely to have their grandchildren in treatment programs for behavior problems; 40% had sought help for their grandchildren; and 25% intended to seek help. Eight to ten percent of the grandparents acting as custodial caregivers were in individual counseling or therapy; less than 25% were in support groups or group therapy. Custodial grandparents frequently had negative perceptions of their relationships with their other grandchildren, that is, less time or energy to spend with them. Raising grandsons appeared to affect the grandparents' psychological functioning more negatively. Although grandparents acting as custodial caregivers adjusted to their role over time,

they still perceived grandparenting in a more traditional way. The traditional grandparents may participate in their grandchildren's lives as family historian, dispenser of wisdom, friend, or temporary emergency support but not involved in the daily responsibilities of primary caregiving.

Burton (Focus on Research, 1992a) conducted a study of the effect of teenage childbearing on the family roles of African-American women. Young grandmothers who had been pushed into early grandparenthood by their daughters' teenage pregnancies were often unwilling to take on the role of surrogate parents. These young grandmothers usually still had parental obligations of their own and often resented the new responsibility. The burden of care was pushed up the generational ladder so that great-grandmothers became the primary caregiver of their young great-grandchildren.

Burton also studied a support group of African-American grandmothers whose members tended to be great-grandmothers in their 60s and 70s with primary caregiver responsibility of one or more great-grandchildren. The primary reason for this arrangement was chronic drug use by the grandchildren's or great-grandchildren's parents. Participants in Burton's support group were often found to be in poor health and overwhelmed by family responsibilities. The key needs identified by the grandparents and great-grandparents were related to respite care, physical and mental health care for themselves, legal counseling concerning foster care and guardianship for their grandchild or great-grandchild, financial assistance, and training programs for coping with drug dependent family members.

Dressel and Barnhill (1992) presented a case study of a national demonstration project addressing various needs of typical three-generation families of imprisoned women--the women themselves, their children, and the grandmother caretakers of the children. Eight grandmothers participated in the

full complement of intergenerational programs: parenting courses, counseling. Additional data from over 150 service contacts with other grandmothers who were custodial caregivers but not part of the demonstration project were included. The grandmothers were from African-American families experiencing considerable financial difficulties.

Grandmothers reported to Dressel and Barnhill (1992) that they had to give up outside employment in order to manage the growing requirements of primary caregiving to their grandchildren. Grandmothers reported that they were unable to tend to the time-consuming tasks of interfacing with officials from service and assistance agencies on their time schedules and meet work obligations also. Grandmothers experienced numerous material, legal, and psychosocial needs such as depression and anxiety. Although grandmothers found satisfaction in their grandchildren's accomplishments and growth, there were also heavy burdens of responsibility and circumstance. The transition into and around assuming primary caregiving responsibilities involved critical issues of family relationships and individual family members' identities not only for grandmothers but also other family members. Grandmothers had no one with whom they could reliably share or divide the caregiving tasks over any meaningful period of time. Therefore, grandmothers assumed full responsibilities for grandchildren's material and psycho-social well-being. Grandmothers also assumed primary caregiving responsibilities for other grandchildren, unemployed adult children, and their elder parent(s). Grandmothers reported feelings of exhaustion and depression.

Jendrek (Focus on Research, 1992b) examined the kind of parenting roles that grandparents assume. The circumstances under which grandparents take on these roles and the consequences to grandparents of becoming caregivers to their grandchildren were also investigated. Other factors Jendrek

examined were the grandparents' decision either to involve the courts in obtaining legal access to grandchildren or to provide care without involving the courts and the kind of programs and services grandparents use or would find helpful in raising their grandchildren. Jendrek interviewed 127 grandparents. The grandparents provided regular care to their grandchildren; the majority were Caucasian, female, and married with the spouse living in the household. The participants' ages ranged between 41 and 74 years with a median age of 56 years.

Grandparents assumed a variety of caregiving roles, ranging from complete assumption of parenting to regular day-care. Forty of the grandparents had a legal relationship (adoption, custody, guardianship) with their grandchildren; 30 lived with their grandchildren without establishing a legal relationship; and 56 provided routine day-care for their grandchildren. Grandparents' major reasons for initiating care of grandchildren included parent's abuse of substances, physical neglect of the grandchildren, parents not married when the grandchildren were born, parent(s) were teenagers, parents working full time and unable to pay for child care, and a desire to help grandchildren's parents financially.

Grandparents reported no change in who their close friends were as a result of providing routine day-care to their grandchildren. Grandparents with a legal relationship were more likely to report changes in their friends than were grandparents who lived with their grandchildren without a legal relationship. Grandparents who had grandchildren living with them or who had a legal relationship with their grandchildren reported major changes in their leisure activities, whereas grandparents who only provided day-care reported far fewer changes. Most of the grandparents did not seek help from social service agencies in trying to provide care to their grandchildren. Grandparents who did

contact social services for help were usually seeking help in obtaining public medical insurance for their grandchildren. Many grandparents noted problems in trying to get their grandchildren covered on their health insurance policy and the extraordinary expense of buying a separate policy for their grandchildren.

A major theme of grandparents with a legal relationship to their grandchildren was that this was not what they had planned. Grandparents had assumed their children would leave home and their grandchildren would live elsewhere. A second major theme in grandparents' responses was that the day-to-day responsibility of providing care for their grandchildren left them feeling more like a parent than a grandparent.

Droddy (Focus on Research, 1993c) investigated the unrecognized family structure of grandparents raising grandchildren. The participants were 59 grandmother caregivers, ranging in age from 46 to 65 years. The grandmothers were married and employed outside the home. Parental substance abuse was the primary reason these grandparents were raising their grandchildren. No link was found between the conflicts experienced by the grandparent caregivers or the lifestyle changes demanded by caregiving and the grandparents' health, income, age, education, employment, or race. Droddy concluded that there may be some universal adjustments and conflicts experienced by grandparents raising grandchildren, regardless of individual family circumstances.

#### Summary of custodial grandparents

Although limited, results from investigations into grandparents assuming primary caregiving responsibility for their grandchildren indicate some similarities to and differences between parents of children with disabilities and custodial grandparents. Both groups are experiencing additional financial and psycho-social stress and have smaller support groups. Also similar to the



demands expressed by the parents were the grandparents' demands for (a) respite care to give them time for themselves and other family members, (b) financial assistance to meet the physical and psycho-social needs of their grandchildren and themselves, and (c) information regarding the legal aspects of caring for their grandchildren or great-grandchildren. Another area of informational demand expressed by grandparents was their need to learn strategies for coping with the circumstances that led to their assuming custodial caregiving responsibilities. However, the degree of hardship these additional stresses cause could be magnified for custodial grandparents who might be on fixed budgets, have personal health problems, suffer from depression and anxiety, and who are tired and overextended.

Not only do custodial grandparents or great-grandparents provide care for their grandchildren but also possibly for other family members' and nonfamily members' children (fictive kin), their own children, a spouse or partner, or elderly parents while trying to work outside the home. Perhaps the biggest difference and stressor is that grandparents did not anticipate raising their grandchildren or dealing with the stressful circumstances which necessitates their acting as custodial caregivers. Factors which mediate grandparent's demands and capabilities included grandchild's gender and grandparent's age.

The information provided through these investigations of custodial grandparents begins to provide insight into the similarities and differences in the demands, capabilities, and adaptation and mediating factors of custodial parents and custodial grandparents. The use of the FAAR Model may assist in understanding the differences and the unique demands and capabilities of these nontraditional families and help explain the adaptation of grandparents raising young grandchildren. Whether this information is representative of

grandparents raising young grandchildren with disabilities or at risk for disabilities remains unclear. It may be that custodial grandparents of young children with disabilities or at risk for disabilities have additional demands, access alternative support systems, and adapt in different ways. Investigations of this population of grandparents is taking place on a limited basis. In the next section I review six such studies.

### Custodial Grandparents of Young Children with Disabilities or At Risk

The commonalties and differences between custodial grandparents of typically developing grandchildren and grandchildren with disabilities or at risk for disabilities have not been established in the research. Investigators are beginning to explore the unique situations of grandparents raising young grandchildren with disabilities or at risk for disabilities. However, as with the family research, this research focuses on a small subgroup of the entire population. As you will note in the following review of the literature, the primary risk group under investigation has been grandchildren prenatally and environmentally exposed to crack cocaine. There are also differences between the custodial grandparents in the following studies and the custodial parents in studies previously reviewed. The six reviews presented in this section focus on the demands, capabilities, and adaptation of custodial grandparents raising grandchildren with disabilities or at risk for disabilities. Not only do the grandparents represent an older population but a larger percentage of them are African-American from lower socioeconomic status.

### Literature review of custodial grandparents of young children with disabilities or at risk

Burton (1992) conducted two qualitative studies involving 60 African-American grandparents and great-grandparents raising their grandchildren.

Participants had no consistent economic or social support from their extended kin network. These studies addressed three research questions:

1. What were the contextual, familial, and individual stressors faced by grandparents who are totally responsible for the care of children of drug-addicted parents?

2. What were the rewards and liabilities of surrogate parenting for grandparents?

3. What types of social services did grandparents indicate they need to facilitate their surrogate parent role?

Data were collected using field observation, focus groups, life history interviews, participant observation, and in-depth interviews. The participants in the first study were predominantly urban, African-American, low socioeconomic status, and from working-class families. Fifteen African-American women, ages 43 to 70, participated in the first study. Eight of the women were married, two were divorced, two were separated, and three were widowed. All but two of the women considered themselves to be barely getting by financially. Five of the women were employed, four received welfare, three were on leave of absence from their job, and three were retired. Eight of the women were maternal grandmothers, three were paternal grandmothers, and four were maternal great-grandmothers. The number of children being raised by the women ranged from two to five, the children's ages ranged from 2 months to 13 years. Two of the grandchildren had physical problems related to their mothers' substance abuse during pregnancy

The participants in the second study were comparable to those in the first study in regard to their community background. Twenty-seven maternal grandmothers, ages 46 to 69 years; 1 paternal grandmother, age 52; 7 maternal great-grandmothers, ages 57 to 82; and 10 maternal grandfathers, ages 62 to

75, participated in the second study. Three of the women and 6 of the men were married; 10 women and 1 man were divorced; 8 women were separated; 6 women and 1 man were widowed; and 2 men had never been married. The majority of the women and half the men perceived themselves as barely getting by financially. Six women and 4 men were employed; 12 women and 6 men were retired; 14 women received welfare; and 3 women received disability benefits for themselves. The number of children being raised by the grandparents ranged from 1 to 8. The custodial grandchildren's ages ranged from 1 month to 20 years. Four of the children's mothers had taken drugs while pregnant.

Three levels of stressors were related to the grandparents' extended family and custodial caregiving roles. Grandparents experienced contextual stressors such as neighborhood dangers and drug traffic. Familial stressors such as providing care for multiple generations, adult children who were drug dependent, extended kin either in crisis or frail elderly, grandchildren and great grandchildren were also reported by grandparents. Another stressor common to these grandparents was the drain on income caused by their drug-dependent children. Grandparents also experienced individual stressors, including balancing multiple roles in multiple settings, putting their own life on hold, and having no time for themselves. The stress grandparents experienced affected their health. Physical illness was reported by 48% of the grandparents; 36% experienced alcoholism; 61% had increased their smoking; and 86% had experienced depression and anxiety. Grandparents experienced both losses and rewards in their roles as custodial caregivers. An important theme expressed by the majority of the grandparents was that they deeply loved and were committed to their grandchildren and that at times their role of custodial caregiver was very gratifying.

Grandparents reported to Burton they felt they could benefit from receiving both instrumental and emotional support from their church, community, and government agencies. Instrumental support included child care, legal counseling concerning foster care and guardianship, respite care, parenting programs, tutorial programs, economic assistance, job counseling and referral, drug-addiction seminars, and health care. Emotional support included support from friends and neighbors, counseling for depression, anxiety, alcoholism, and smoking. In some cases the grandparents may have been receiving some of these, but they felt the need for additional support. In other cases the support was not easily accessed by the grandparents or was not available at all.

Minkler and Roe (Focus on Research, 1993b) and Minkler, Roe, and Price (1992) reported an in-depth study of the experience of 71 African-American women who were raising young grandchildren or great-grandchildren as a direct consequence of the crack-cocaine epidemic. The women's ages ranged from 41 to 79 years, and each was raising at least one grandchild under the age of 5. Twenty-five percent of the women were married with a husband present in the home. One-third of the women were employed in blue collar positions, and one-third had quit their jobs to become full time caregivers. Quantitative and qualitative interview methods were used to measure the custodial caregiving effects on the grandmothers' physical and emotional health, circumstances surrounding the assumption of the caregiver role, economic costs of caring for the grandchildren, the special challenges of raising children impacted by the drug epidemic, and the caregivers' supports and coping strategies.

Custodial grandparents tended to downplay the severity of their own physical health problems in order to focus on the needs of their adult children or

the grandchildren in their care. Women caring simultaneously for grandchildren and older parents and employed women whose work tasks closely mirrored their caregiving chores were particularly vulnerable. Thirty-four of the women reported having been depressed at some point in the previous week. Most of the caregiving grandmothers reported financial difficulty since becoming custodial caregivers; 70% reported their income was inadequate to meet their needs. Grandmothers identified respite care and more equitable financial assistance as their most critical unmet needs. Another unmet need of the custodial grandparents was accessible social support groups. The caregiving grandmothers were deeply concerned for the future of their grandchildren and their ability to keep up and make ends meet.

Working grandmothers were significantly more likely to rate their health as excellent or good. Over half of the grandmothers reported their health to be good or excellent. Forty-five percent of the grandmothers stated that their health never got in the way of things they wanted or needed to do; however, they qualified this response with "it can't." Three times as many grandmothers reported themselves to be in excellent emotional health as had rated their physical health to be excellent. Again, many qualified this with "how could I deal with all this otherwise." Even among those grandmothers who rated their emotional health as good or excellent, there were frequent reports of feeling lonely or depressed. Seventy-two percent of the grandmothers reported feeling depressed at least some of the time during the past week; 70% had felt they could not get going; 78% felt totally exhausted; and 47% felt lonely. Eighty-nine percent of the grandmothers felt appreciated, and 96% felt they were fulfilling their responsibilities.

Grandmothers reported an intense desire to protect the grandchildren in their care and the newfound security of the grandchildren's living situation. One

way grandmothers did this was by downplaying their own health problems. The grandmothers' fear that their grandchildren might be placed in foster care if they were unable to provide care for them appeared to contribute to the frequent discrepancies between their own global health ratings and the details they revealed throughout the interviews about their health.

Perrin (Focus on Research, 1993c) explored the perceptions of burden and coping strategies of 30 grandmothers caring for infant grandchildren who had been prenatally exposed to illicit drugs. Each grandmother completed two questionnaires. In-depth interviews were conducted with 12 of the 30 participants. The majority of the grandmothers experienced moderate to severe degrees of caregiver burden. Grandmothers most often reported feelings of helplessness, resentment, and anger. The coping strategy most frequently used by caregiving grandmothers was talking with others. An important observation was that, although frustrated, the grandmothers were determined to fulfill the needs of their grandchildren

Seamon (1993) conducted a study to learn more about the role of elderly African-Americans in drug-addicted families. Specifically, the problems they face, the supports and resources they need, and the dynamics of the situation they deal with on a daily basis were investigated. Seamon interviewed 10 grandmothers, ages 45 to 76 years; 3 grandfathers, ages 56 to 70 years; and 2 elderly women, ages 50 and 65 years, who were caring for children of various relatives. The majority of the participants lived in public housing, although 6 lived in their own homes. All but 1 of the participants were on social security. The number of dependents being cared for by the grandparents ranged from 2 to 7.

Major issues for these grandparents were (a) concern for their own safety and security as well as that of the grandchildren in their care and of addicted

family members, (b) the theft of material goods and Social Security checks to exchange for money or drugs, and (c) physical violence or threats of violence. Their concern for their safety and the safety of their families caused stress, poor health, and sleepless nights. Other concerns expressed by the grandparents were the burden of caring for their grandchildren, the children of relatives or neighbors, as well as caring for their adult children who were addicted to crack. Grandparents reported that caregiving at this stage in their life is both physically and emotionally demanding and very stressful. A particular stress grandparents experienced was concern about what would happen when they could no longer care for their grandchildren. Grandparents expressed the need for additional resources and support.

In order to meet their caregiving demands, grandparents dipped into their savings and sought help from relatives, friends, and church. The grandparents' informal support systems were a major factor in their ability to continue in the caregiving role. Grandparents expressed their need for emotional support, especially in understanding and dealing with their adult children's addiction to crack.

#### Summary of custodial grandparents of young children with disabilities or at risk

Custodial grandparents of young children with disabilities or at risk for disabilities experience many of the same demands as the parents of children with disabilities and the custodial grandparents discussed in the previous sections. The custodial grandparents discussed in this section experienced demands for accessible social support groups, respite care, more equitable financial assistance, information regarding the legal and parenting aspects of their role, and planning for their future and the future of their grandchildren. However, there were differences between these grandparents and the parents of children with disabilities discussed previously. The grandparents reported



demands arising from an unsafe environment resulting from poverty, violence, and substance abuse as well as dealing with their children's substance abuse. Grandparents also reported the physical and psycho-social stress of their multiple caregiving roles, such as caring for elderly relatives, a spouse or partner, adult children, their own young children, grandchildren, and fictive kin. Additional stress came from their multiple noncaregiving roles, including employment outside of the home, involvement with church, and other community projects. Physical stress due to the grandparents' age and ill-health was also experienced.

The grandparents' capabilities to meet these demands focused on downplaying their own health problems, dipping into their personal savings accounts, and informal support systems of friends, relatives, and church. To help them adapt to the demands they experienced, grandparents relied on their love for their grandchildren and their commitment to protect them.

The majority of the investigations reviewed in this section focused on minority grandparents from lower socioeconomic status backgrounds whose custodial grandchildren's parents were involved in substance abuse. The effect of their status on the demands, capabilities, and adaptation of this sample of grandparents is unclear. Although this sample is not representative of all grandparents who are raising young grandchildren with disabilities, the research reviewed in this section is a starting point. Similarities as well as differences within and between parents of children with disabilities, custodial grandparents of typically developing children, and custodial grandparents of children with disabilities are emerging. The use of the FAAR Model may assist in understanding the differences and similarities in demands, capabilities, and adaptation of these nontraditional families. The extent to which these similarities and differences are a result of the custodial relationship or reflect

aspects of the traditional relationship between grandparents and grandchildren remains unclear. Research into the relationship between grandparents and grandchildren is more readily available than research into the relationship between custodial grandparents and grandchildren. In the next section I review 16 of these studies, focusing on the variables which mediate the relationship between grandparents and grandchildren.

### The Relationship Between Grandparents and Grandchildren

The FAAR Model operationalizes family adjustment and adaptation through the relationship between families' perceptions of their demands and capabilities. However, other factors have been documented to mediate the traditional relationship between grandparents and grandchildren. Whether or not these same factors mediate the custodial grandparents' demands, capabilities, and adaptation is unclear. This study explores the relationship of these mediating factors with each of the dependent variables (demands, capabilities, and adaptation). In this section, I have reviewed 16 studies investigating the relationship between grandparents and grandchildren. The focus of each review is on the mediating variables identified in the studies.

### Literature review of the relationship between grandparents and grandchildren

Fischer (1983) described the role perceptions of grandparenthood for grandmothers and suggested how these role perceptions may be modified by variations in the family network. This study was an exploratory study of 28 grandmothers, ages 43 to 64 years. Results of the study indicated that lineage (maternal vs. paternal relationship) determined how accessible grandparents' role relationships were with their grandchildren.

Johnson (1983) identified the ways grandmothers of divorced children conceptualized their role, made decisions about their behaviors as grandparents, and arrived at rules that would govern their interactions with their

grandchildren. Qualitative data were collected through interviews with 58 grandmothers of divorced children. The majority of the grandmothers were Caucasian, middle-class, and from suburban areas. Half of the participants were maternal grandmothers and half were paternal grandmothers. The ages of the grandmothers varied; half were under 65 years of age and half were 65 years of age or older. Results indicated that age was a mediating factor in grandparent-grandchildren relationships. The older grandmothers in Johnson's study were less active with their grandchildren; however, this is believed to be an effect of the grandchildren's age rather than the grandmothers age.

Thomas and Datan (1983) explored change over time in grandparenting experiences, sex differences in grandparenting, and differences among relationships with different grandchildren. Thirteen grandmothers and 6 grandfathers, ages 52 to 78, were interviewed. Results indicated that grandparenting activities changed as the grandchildren aged. An example of this is that grandparents participation in caretaking and baby-sitting behaviors occurred less often for older grandchildren. Also, grandparents' irritations with their grandchildren's disobedience and carelessness increased as the grandchildren aged. Although the majority of grandparents enjoyed outings with their grandchildren, grandmothers enjoyed them more than grandfathers. More grandmothers enjoyed baby-sitting than did grandfathers. There were gender differences in grandparenting. One example is that grandfathers gave practical help while grandmothers provided comfort and helped resolve conflict between the grandchildren and their parents. Another example is that grandfathers perceived grandparenting as an experience leading to their own personal growth while grandmothers saw it as a reflection of their grandchildren's parents' personal growth.

Mathews and Sprey (1984) added to an understanding of grandparent behavior in general and the impact of divorce in the middle generation on the extended kinship network. Thirty-seven grandparent couples from Caucasian middle socioeconomic backgrounds were interviewed. Eighteen of the couples had children who had divorced, and 19 had no divorced children. Mathews and Sprey found that maternal grandparents were in a better position to maintain relationships with their grandchildren and were more likely to be called upon for financial and emotional support. Overall, the majority of grandparents perceived the age of their grandchildren and age of the grandchildren's parents as influencing their contact with their grandchildren. For example, grandparents were more involved when the grandchildren's divorced parent was younger.

Thomas (1984) examined gender differences in grandparent satisfaction and perceptions of their role as grandparents. The grandparents' ages ranged from 45 to 90 years. Grandmothers (N = 177) and grandfathers (N = 105) completed a mail-out survey addressing grandparent satisfaction, perceived responsibility for their grandchildren's discipline, care, giving help to grandchildren, and giving childrearing advice to their grandchildren's parents.

Gender differences were found in grandparent satisfaction and in certain areas of perceived responsibility. Grandmothers were more satisfied with their grandparenting than were grandfathers. Grandfathers perceived that they had a greater responsibility for caregiving and giving childrearing advice than did grandmothers. However, no gender differences were found in perceived responsibility for disciplining or giving help to grandchildren.

Gender differences were also found in demographic characteristics of the grandparents. Grandmothers were more likely than grandfathers to be separated or divorced and to be full-time homemakers, semi-retired, or work

part-time. Grandmothers were also less likely to have completed college and to be working outside the home.

Bengston (1985) noted two principal themes emerging from studies of grandparenthood: diversity and symbolism in the grandparent role. Information was collected from three empirical sources: (a) a study of 2,044 members of three-generation families, that is, grandparent, parent, and grandchildren; (b) interviews with 1,428 middle-aged and elderly African-American, Mexican-American, and non-Hispanic Caucasians; and (c) participant observation of his personal family. Overall, grandparents appeared to be heterogeneous and serve a mainly symbolic function, that is, family historian, simply being there but not intruding into the daily routine of the family.

Bengston also noted gender differences in the responses of the participating grandparents. Grandmothers had higher affect than grandfathers. Grandfathers were closer to grandsons than to granddaughters. Younger members of each generation reported more family strain and conflict than did older members of each generation.

No minority versus Caucasian pattern was documented; however, there were important ethnic differences in potential support systems. Clear differences among ethnic groups were also demonstrated in relations between the generations of the family and persons in the family but not related to the family ("fictive kin"). Mexican-American grandparents had more children and grandchildren than did African-American or Caucasian grandparents and thus may have had a larger potential source of social support. Mexican-American grandparents also had more contact with their children and grandchildren. Mexican-American grandparents were more satisfied with their contact with their children and grandchildren.

Kivett (1985) explored grandfathers' patterns of association with and assistance to their grandchildren, perceptions of their relationships with their grandchildren, and factors associated with their interaction patterns and perceptions. Ninety-nine grandfathers representing urban and rural locations completed a questionnaire measuring their association, in terms of their interactions and communications, with their grandchildren.

Kivett found that age and sex of the grandchildren and health of the grandfather had no importance to the grandfathers' association with their grandchildren. However, grandfathers' perceptions of their closeness with their grandchildren decreased as age of the grandchildren increased. In general, the grandfather perceived their other family roles, that is, son, spouse, and parent, and to social roles to be supraordinate to their grandparent role.

Thomas and Sanders (1985) examined age and gender differences in perceived grandparenting responsibilities. Grandmothers and grandfathers were divided into three age groups. The first group consisted of younger grandparents who were 45 to 60 years of age (N = 29 grandmothers, N = 21 grandfathers). The second group consisted of grandparents who were 61 to 69 years of age (N = 70 grandmothers, N = 39 grandfathers). The last group consisted of older grandparents who were 70 to 90 years of age (N = 73 grandmothers, N = 45 grandfathers). All participating grandparents were Caucasian. Mail-out questionnaires were completed by the grandparents.

Results from the study indicated that younger grandparents had a higher income and were more likely to be in the work force full-time. Grandparents between the ages of 61 and 90 were more likely to be retired, widowed, have smaller numbers of children and grandchildren, and have older grandchildren. Grandfathers were more likely to be married, better educated, and work outside the home in full-time positions.

Grandparents between the ages of 45 and 69 perceived their responsibility for discipline, caregiving, and offering childrearing advice to be greater than did the older grandparents. There was no significant difference between age groups for grandparenting satisfaction or level of perceived responsibility for helping their grandchildren. Grandmothers were more satisfied than grandfathers were with grandparenthood and perceived their responsibility for caregiving and offering childrearing advice to be less. There were no significant gender differences in perceived responsibility for discipline or helping grandchildren. Grandparents perceived their responsibility to discipline their grandchildren and give them advice to be less for their older and younger grandchildren. Grandparents also perceived they had less responsibility to provide caregiving to their oldest grandchildren. Grandparents were most satisfied with grandparenting their youngest grandchildren. Finally, the more grandchildren grandparents had, the less their perception of responsibility for caregiving and disciplining their grandchildren.

Cherlin and Furstenberg (1986) examined the role of grandparents in families. Grandparents (N = 510) from throughout the United States of America were interviewed. According to the results, the dominant style of grandparenting was based on pleasurable interactions and affection, being a companion not a parent to the grandchildren. Although African-American grandparents share the belief in grandparent autonomy common among grandparents, they felt their involvement with their grandchildren had to be more functional and parent-like. This perception was not common to the other grandparents participating in the study.

Cherlin and Furstenberg found gender, lineage connection, and age differences within their sample. Overall, grandfathers had more leisure time than did grandmothers. Young grandmothers were more likely to be employed

and caring for their aged parents and, therefore, had less time to devote to their grandchildren. Grandparents also had a higher living standard than past generations and were, therefore, less dependent on and obligated to their adult children. Maternal grandparents had closer ties, more contact, and more parent-like behavior than did paternal grandparents. Younger grandparents were more parent-like in their behaviors.

Baranowski, Schilmoeller, and Forscher (1987) examined grandfather-grandchildren interaction patterns and the personal meaning of grandfatherhood. Interviews and questionnaires were completed by 106 Caucasian, married grandfathers, ages 40 to 84 years. Information was collected regarding the grandfather-grandchildren interactions, grandparenthood meaning, and the grandchildren's ages. Results indicated that older grandfathers had less contact with their grandchildren. Also, grandfathers saw their older grandchildren less often than their younger grandchildren.

Hettinger (1989) also examined grandparenting. Questionnaires were completed by 44 grandmothers and 30 grandfathers over the age of 65 years. Hettinger identified a variety of factors which mediated grandparent satisfaction. Results indicated that grandparents' age, age at which they became grandparents, lineage connection, and frequency of contact all contributed to role satisfaction for grandparents.

Thomas (1989a) examined associations between grandparents' gender and their perceptions of grandparenting through structured interviews with 115 grandfathers and 186 grandmothers. The grandparents ranged in age from 43 to 86 years. Information was collected regarding grandparent perceptions of their relationships with their grandchildren. Again, gender differences were found. Grandmothers expressed greater grandparenting satisfaction than did



grandfathers. Gender difference was not noted in grandparents' perceived responsibility toward their grandchildren or the centrality of their relationship with their grandchildren in their lives. Differences were not noted in the extent to which the grandparent-grandchildren relationship allowed for grandparents' reinvolvement with their past or the extent to which grandparents valued sharing their wisdom with their grandchildren.

Thomas (1989b) also explored the relationship between grandparent-parent solidarity on grandparents' perceptions of grandparenthood and their mental health. Interviews were conducted with 301 Caucasian grandparents, ages 43 to 86 years. Questionnaires were used to measure grandparenting satisfaction and perceived responsibilities. The meaning of grandparenthood was measured in regards to oldest grandchildren from a two-parent family living in closest proximity to the grandparents. Interview questions also addressed the frequency of contact and help exchanges with grandchildren and grandchildren's parents, attitudinal similarities with grandchildren's parents, and their affect towards the grandchildren's parents.

Results indicated that good health and frequent intergenerational contact were predictors of grandparents' morale. Furthermore, good health, marital status (married), and attitudinal similarities with grandchildren's parents were predictors of the grandparents' positive life satisfaction. Good health, marital status (married), and low symbolic meaning of grandparenthood were also predictors of the grandparents' positive self-esteem.

Pearson, Hunter, Ensminger, and Kellan (1990) identified the types of roles grandmothers played in households where they shared a residence with their grandchildren. A cohort of first graders ( $N = 1,400$ ) and their families ( $N = 1,391$  mothers/surrogates) in Chicago's Woodlawn community were

interviewed. One hundred thirty-eight of the extended families had grandmothers residing in the household.

Results indicated that grandmothers' age was not related to their engagement in individual parenting behavior. Supportive behavior was the most frequent parenting behavior from all extended family members, except the grandfather. Grandmothers were the primary caregivers more frequently than were grandfathers. Grandmothers acting as surrogate mothers were more involved in parenting behaviors than grandmothers in families with mothers present. Also, in families with mothers absent, grandmothers were also more involved in control and punishment of their grandchildren. In general, regardless of the status of the mother in the home, grandmothers' employment status did not affect their engagement in individual parenting behaviors.

Huish (1991) identified ethnic differences in grandparents' perceptions of their role performance and effectiveness. The participants were 204 Caucasian and 204 African-American grandparents. Additionally, 175 Caucasian and 295 African-American grandchildren of the grandparents participated in the study. Measures of grandparent satisfaction, success in the grandparent role, teaching lessons to grandchildren, handling difficulties of grandparenting, handling frustration with grandchildren, and information about grandchildren were obtained through a questionnaire.

Huish noted that African-American grandparents perceived themselves more favorably on all six subscales, that is, grandparent satisfaction, success in the grandparent role, teaching lessons to grandchildren, handling difficulties of grandparenting, handling frustration with grandchildren, and information about grandchildren. African-American grandchildren scored their grandparents significantly more favorably in success in the grandparent role and teaching lessons to grandchildren. Caucasian grandchildren scored their grandparents

higher on handling difficulties of grandparenting, handling frustration with grandchildren, and information about grandchildren.

Significant main effects were also found for grandparents' age, grandchild's age, grandparents' tie with grandchildren, and geographic proximity of the grandchildren to the grandparents. No significant effects were found for grandparents' gender. Interaction effects were found for ethnicity by age of grandparent, ethnicity by age of grandchildren, location by time, and ethnicity by distance.

For example, African-American grandparents over the age of 60 years and Caucasian grandparents under the age of 60 years perceived themselves as more effective in their grandparenting role. Caucasian and African-American grandparents perceived themselves to be more successful with young grandchildren (ages 12 and younger). Caucasian grandparents spent more hours per month with younger grandchildren while African-American grandparents did not perceive their grandchildren's age as affecting the amount of time they spent together. African-American grandparents spent more hours per month with their grandchildren than did Caucasian grandparents. Caucasian grandparents with closer proximity to their grandchildren perceived themselves as more successful grandparents, more effective teachers, and better able to manage difficulties than did African-American grandparents. African-American grandparents, on the other hand, did not consider distance to be a factor in their expectations of themselves or their effectiveness as grandparents.

In general, the more time a grandparent spent with a grandchild, the more effective they perceived themselves to be in the grandparent role. Overall, grandmothers were perceived as more effective teachers and grandfathers were perceived as better able to cope with frustrations.

Strom, Collinsworth, Strom, and Griswold (1993) studied the same data as Huish, identifying ethnic differences in grandparents' performance and effectiveness. Their results also indicated that African-American grandparents perceived themselves to be more involved in all six areas, although African-American grandparents perceived teaching as their strength. African-American grandparents reported spending more hours per month with their grandchildren than Caucasian grandparents did. Caucasian grandparents with closer proximity to their grandchildren perceived themselves as more successful grandparents, more effective teachers, and better able to manage difficulties. African-American grandparents did not consider distance to be a factor in their expectations of themselves or their effectiveness. African-American grandparents over the age of 60 years and Caucasian grandparents under the age of 60 years perceived themselves as more effective in their grandparenting role. Caucasian and African-American grandparents perceived themselves to be more successful with grandchildren aged 12 and younger. Caucasian grandparents spent more hours per month with younger grandchildren while African-American grandparents did not perceive grandchildren's age as affecting the amount of time they spent together. Overall, grandmothers were perceived as more effective teachers and grandfathers were perceived as better able to cope with frustrations.

#### Summary of the relationship between grandparents and grandchildren

The empirical research from the past decade on the relationship between grandparents and grandchildren documented the existence of mediating factors in this relationship. The factors included the grandparents' age, age of entry into grandparenthood, gender, race, marital status, health status, socioeconomic status, and lineage connection to the grandchildren, as well as the grandchildren's age and gender. Older grandparents tended to be less

involved in the functional aspects of discipline and caregiving. Women who became grandmothers either too early or too late in their life cycle (before 40s and after 60s) were not as involved or pleased with the role of grandmother. Grandmothers were more involved in the caregiving aspects of grandparenting than were grandfathers. Although there were not statistically significant ethnic differences in grandparenting, African-American grandparents had a history of extended family support systems and caregiving behaviors. Married grandparents and those with good health were more active in the grandparenting role and more satisfied with their role. Maternal grandparents, especially grandmothers, took on the role of surrogate parent more often in times of crisis or need than did paternal grandparents. Grandparents were more involved in caregiving for younger grandchildren than for older grandchildren. In general, grandfathers were more involved with grandsons than granddaughters and grandsons caused more stress than granddaughters.

Based upon studies reviewed in this chapter, we have identified demands, capabilities, adaptation, and mediating factor differences and similarities between parents of children with disabilities, custodial grandparents of typically developing grandchildren, and custodial grandparents. The extent to which the mediating factors identified in this section affect these demands, capabilities, and adaptation remains unclear.

Based upon parent report we know that their marital status, gender, race, and child's gender can magnify their perceptions of their demands, capabilities, and adaptation. Based upon grandparent reports we know that their age, marital status, health status, and socioeconomic status can magnify the degree to which they experience the demands of primary caregiving to young grandchildren. We also know that these factors influence the capabilities custodial grandparents use to balance their demands and adapt to their family

circumstances. This study was designed to investigate the relationships and interactions of these mediating factors to the perceived demands, capabilities, and adaptation of grandparents raising young grandchildren with disabilities or at risk for disabilities.

### Literature Not Used

Literature searches focusing on families of children with disabilities or at risk for disabilities uncovered literature that was child- and program-oriented or described intervention strategies and modules. Literature searches also uncovered studies that did not directly relate to this study or were in a language other than English. Studies that did not directly relate to this investigation included studies (a) whose research subjects were not Americans, (b) whose respondents were the adult children or grandchildren of the grandparents and provided their perceptions of their parents or grandparents, (c) that were reviews of the literature, and (d) that focused on grandparent education or how to grandparent.

### Summary

The literature reviewed in this chapter provides a theoretical and empirical basis for the study of custodial grandparents raising young children with disabilities or at risk for disabilities. Federal and state policies regarding the education of young children with disabilities and at risk for disabilities necessitate that professionals understand how to involve families as equal partners in their children's educational services. Educators as well as other related service personnel need to (a) understand the process of family adjustment and adaptation; (b) understand the interactive role of custodial grandparents' demands, capabilities, and meaning; and (c) assess the family's unique demands and capabilities. Professionals who have met these criteria can assist the family in developing capabilities which balance their demands,

thereby maintaining balanced functioning in either the adjustment or adaptation stage.

The results of empirical studies investigating families of children with disabilities, custodial grandparents, and the grandparent-grandchildren connection provide a basis on which to build this investigation. Identifying not only the demands, capabilities, and adaptation of custodial grandparents' of young children with disabilities or at risk for disabilities but also the interactions of these with the grandparents' age, age of entry into grandparenthood, gender, race, marital status, health status, socioeconomic status, and lineage connection to the grandchildren, as well as the grandchildren's age and gender affecting these, will provide insight into the functioning of members in this nontraditional family structure. Similarities as well as differences have been identified between and among parents of children with disabilities, custodial grandparents, and custodial grandparents of children with disabilities. However, this information is based upon studies of limited generalizability due to the homogeneity of the participating populations. This study expands current knowledge not only regarding family systems theory but also families representing diverse structures, races, genders, and socioeconomic status.

The information derived from this study should also assist in identifying and understanding the interactive process through which the custodial grandparents' adjustment or adaptation is affected. Furthermore, the results of this study should enable early childhood special education personnel, as well as other related service personnel, to develop and implement sensitive and appropriate services as well as documents (e.g., Individualized Educational Programs and Individualized Family Support Plans). Using their knowledge of the custodial grandparents' perceived demands, capabilities, and level of functioning, the relationship between them, and the factors which may mediate

these perceptions early childhood special education personnel should be able to facilitate family involvement in the education of young children with disabilities or at risk for disabilities.



## CHAPTER THREE METHODS AND PROCEDURES

### Introduction

The purpose of this study was to investigate the relationship between the demands, capabilities, and adaptation of grandparents raising young grandchildren with disabilities or at risk for disabilities and other key variables that have received extensive study in the area of the relationship between grandparents and grandchildren. The data from this study were used to make inferences about Family Systems Theory and the operational Family Adjustment and Adaptation Response (FAAR) Model in regards to a nontraditional family structure--the custodial grandparent and grandchild family. In this chapter, I first state the research hypotheses that guided the investigation. Second, I discuss the nature of the participants. Third, I review the current status of family assessment instruments. Fourth, I identify the instruments, with special attention to available data on reliability and validity. Fifth, I explain the procedures involved in data collection. Last, I discuss the treatment of the data.

### Description of the Hypotheses

Six null hypotheses were tested. They are stated below in their null form. Although the null hypotheses were tested, certain relationships are expected between the independent and dependent variables based on the literature on grandparent and grandchild relationships. A statement of this relationship is also included with each null hypothesis.

H1: The custodial grandparents' age, gender, race, marital status, health status, socioeconomic status, lineage connection to the grandchild, and

the grandchild's age and gender are not related to the custodial grandparents' perception of their demands.

H1.1: The custodial grandparents' age is not related to their perception of their demands. It is expected that younger grandparents will perceive more unmet demands.

H1.2: The custodial grandparents' gender is not related to their perception of their demands. It is expected that grandmothers will perceive more unmet demands.

H1.3: The custodial grandparents' race is not related to their perception of their demands. It is expected that minority grandparents will perceive more unmet demands.

H1.4: The custodial grandparents' marital status is not related to their perception of their demands. It is expected that grandparents who are married, remarried, or living with a partner will perceive less unmet demands.

H1.5: The custodial grandparents' health status is not related to their perception of their demands. It is expected that grandparents whose health is excellent or good will perceive less unmet demands.

H1.6: The custodial grandparents' socioeconomic status is not related to their perception of their demands. It is expected that grandparents with a higher annual family income will perceive less unmet demands.

H1.7: The custodial grandparents' lineage connection is not related to their perception of their demands. It is expected that grandparents raising their son's child will perceive more unmet demands.

H1.8: The grandchild's age is not related to the custodial grandparents' perception of their demands. It is expected that grandparents raising older grandchildren will perceive more unmet demands.

H1.9: The grandchild's gender is not related to the custodial grandparents' perception of their demands. It is expected that grandparents raising grandsons will perceive more unmet demands.

H2: The custodial grandparents' age, gender, race, marital status, health status, socioeconomic status, lineage connection to the grandchild, and the grandchild's age and gender are not related to the custodial grandparents' perception of their capabilities.

H2.1: The custodial grandparents' age is not related to their perception of their capabilities. It is expected that older grandparents will perceive their capabilities as more helpful.

H2.2: The custodial grandparents' gender is not related to their perception of their capabilities. It is expected that grandfathers will perceive their capabilities as less helpful.

H2.3: The custodial grandparents' race is not related to their perception of their capabilities. It is expected that Caucasian grandparents will perceive their capabilities as more helpful.

H2.4: The custodial grandparents' marital is not related to their perception of their capabilities. It is expected that grandparents who are married, remarried, or living with a partner will perceive their capabilities as more helpful.

H2.5: The custodial grandparents' health status is not related to their perception of their capabilities. It is expected that grandparents whose health is excellent or good will perceive their capabilities as more helpful.

H2.6: The custodial grandparents' socioeconomic status is not related to their perception of their capabilities. It is expected that grandparents

with a higher annual family income will perceive their capabilities as more helpful.

H2.7: The custodial grandparents' lineage connection is not related to their perception of their capabilities. It is expected that grandparents who are raising their daughter's child will perceive their capabilities as more helpful.

H2.8: The grandchild's age is not related to the custodial grandparents' perception of their capabilities. It is expected that grandparents who are raising younger grandchildren will perceive their capabilities as more helpful.

H2.9: The grandchild's gender is not related to the custodial grandparents' perception of their capabilities. It is expected that grandparents who are raising granddaughters will perceive their capabilities as more helpful.

H3: The custodial grandparents' age, gender, race, marital status, health status, socioeconomic status, lineage connection to the grandchild, and the grandchild's age and gender are not related to the custodial grandparents' perception of their demands.

H3.1: The custodial grandparents' age is not related to their perception of their adaptation. It is expected that younger and older grandparents will perceive poorer family adaptation.

H3.2: The custodial grandparents' gender is not related to their perception of their adaptation. It is expected that grandmothers will perceive better family adaptation.

H3.3: The custodial grandparents' race is not related to their perception of their adaptation. It is expected that minority grandparents will perceive better family adaptation.

H3.4: The custodial grandparents' marital status is not related to their perception of their adaptation. It is expected that grandparents who are married, remarried, or living with a partner will perceive better family adaptation.

H3.5: The custodial grandparents' health status is not related to their perception of their adaptation. It is expected that grandparents whose health is excellent or good will perceive better family adaptation.

H3.6: The custodial grandparents' socioeconomic status is not related to their perception of their adaptation. It is expected that grandparents with a higher annual family income will perceive better family adaptation.

H3.7: The custodial grandparents' lineage connection is not related to their perception of their adaptation. It is expected that grandparents who are raising their daughter's child will perceive better family adaptation.

H3.8: The grandchild's age is not related to the custodial grandparents' perception of their adaptation. It is expected that grandparents who are raising younger grandchildren will perceive better family adaptation.

H3.9: The grandchild's gender is not related to the custodial grandparents' perception of their adaptation. It is expected that grandparents who are raising granddaughters will perceive better family adaptation.

H4: The custodial grandparents' perception of their demands is not related to their perceptions of their capabilities.

H5: The custodial grandparents' perception of their demands is not related to their perceptions of their adaptation.

H6: The custodial grandparents' perception of their capabilities is not related to their perceptions of their adaptation.

### Family Assessment Instruments

Instruments designed to assess whole family functioning have been reviewed in the literature (Grotevant & Carlson, 1990; Halvorsen, 1991; Touliatos, Perlmutter, & Strauss, 1990). These reviews are usually limited to published instruments only. The numerous family assessment scales developed to serve a specific purpose are not included in the published reviews. However, published and experimental instruments often lack documented evidence of their reliability and validity. Furthermore, there is a lack of consistency regarding the instruments used, the definitions of key concepts and outcomes measured, and the theoretical basis of the instrument. There is also a variety of methodology used in data collection.

An important problem of family assessment stems from the complex and abstract nature of the concept of family, which is neither defined nor measured easily (Cowan, Hansen, Swanson, Field, & Skolnick, 1993; deGruy & Dickinson, 1991). Nevertheless, Cowan et al. suggested that practitioners and researchers accept the lack of standardized definitions and simply be explicit about whichever definition they use and outcomes they measure. Another source of problems in assessing families arises from the diversity of theoretical orientations to families. Again, Cowan et al. suggested that practitioners and researchers accept the variety of theoretical orientations, be explicit as to the theoretical orientation of their research, and discuss their choice(s) in respect to family assessment.

Once definitions, outcomes, and theoretical orientation(s) are presented, the method of assessing the family presents additional problems. Family assessment can be conducted in a variety of methods, including case studies,

observations, interviews, and self-report. deGruy and Dickinson (1991) noted that "just as it is not necessary to select a single definition, neither is it necessary to select a single method as the best for collecting data" (p. 18). Cowan, Hansen, Swanson, Field, and Skolnick (1993) stated that "no single method can be allowed to delimit the meaning and reality of our knowledge about families" (p. 466). The choice of methods is largely dependent on the questions being asked and the theoretical or operational model upon which these questions are based.

An important aspect of the Family Adjustment and Adaptation Response (FAAR) model, which is the operational model for this study, is the meaning families ascribe to their demands and capabilities. For this reason, the instruments used in the present study are self-report scales which measure the grandparents' perception of selected aspects (demands, capabilities, and adaptation) of their family. However, several problems concerning both rater competence and psychometric properties arise when self-report questionnaires are used. First, self-report formats are vulnerable to social desirability and other response biases and may be limited by the subjects' awareness of their own perceptions and the expectations of others (Grotevant & Carlson, 1990). Second, self-report scales are limited by their reliability and validity. Unfortunately, few family assessment instruments with adequate reliability and validity data are available (Dunst Cooper, Weeldreyer, Snyder, & Chase, 1988; Grotevant & Carlson, 1990; Halvorsen, 1991). Effort was taken to use scales with demonstrated reliability and validity. However, coefficient alphas were run on the data from this investigation to document internal consistency for the *Family Needs Scale* (Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1987; 1988), the *Family Support Scale* (Dunst, Jenkins, & Trivette, 1984; Dunst, Trivette, & Jenkins, 1988), and the *Family Adaptation and Cohesion Evaluation*

*Scales (FACES) II* (Olson, Portner, & Bell, 1982; Olson, Bell, & Portner, 1991).

The results are reported in Tables 3 through 5. Effort was also taken to use scales with psychometric properties developed on populations that included participants similar to the potential participants of this study.

Table 3

Coefficient Alphas for Family Needs Scale

Factor	Coefficient alpha
Basic Resources	.956
Specialized Child Care	.893
Personal and Family Growth	.816
Financial and Medical Resources	.866
Child Education	.694
Meal Preparation	.916
Future Child Care	.696
Household Support	NA
Financial Budgeting	NA
Total Needs Score	.973

Table 4

Coefficient Alphas for Family Support Scale

Factor	Coefficient alpha
Informal Kinship	.768
Spouse or Partner Support	.762
Social Organizations	.740
Formal Kinship	.593
Professional Services	.708
Total Support Score	.874



Table 5

Coefficient Alphas for Family Adaptation and Cohesion Evaluation Scale II

Factor	Coefficient alpha
Family Cohesion	.796
Family Adaptation	.827
Total Adaptation Scaled Score	.895

Participants

Participants for this study consisted of custodial grandparents of young children, ages birth through 5 years, with disabilities or at risk for disabilities residing in the state who are receiving services from the Department of Health and Rehabilitative Services (HRS) or are members of local grandparent organizations. I solicited assistance from 15 HRS districts and 20 grandparent organizations in the state to identify potential participants (a complete list of contacts is provided in Appendix A). Grandparents' age, gender, race, socioeconomic status, or geographic location within the state of Florida were not factors in their selection. Three hundred seventy-seven survey packets were disseminated. Participation was voluntary and no remuneration was provided to participants.

One hundred thirty-eight surveys were returned. After eliminating surveys that could not be scored due to incomplete responses or ineligibility as a result of age of child or relationship with the child, a sample of 93 grandparents was obtained.

Research Instrumentation

Each participant received a cover letter and a survey booklet. The cover letter was written according to University Institutional Review Board criteria. The

survey booklet consisted of a family demographic survey and three questionnaires: (a) the *Family Needs Scale* (Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1987; 1988), (b) the *Family Support Scale* (Dunst, Jenkins, & Trivette, 1984; Dunst, Trivette, & Jenkins, 1988), and (c) the *Family Adaptation and Cohesion Evaluation Scales (FACES) II* (Olson, Portner, & Bell, 1982; Olson, Bell, & Portner, 1991). Copies of the cover letter and survey booklet are provided in Appendix B. Two criteria guided selection of the instruments. First, the selected instruments had adequate reliability and validity (Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1987; 1988; Dunst, Jenkins, & Trivette, 1984; Olson, Portner, & Bell, 1991). Second, instruments selected for this investigation had previously been used in published studies of families' demands, capabilities, or adaptability. Permission to use each of the scales was received from the authors.

#### Family Demographic Survey

Empirical investigations of the relationship between grandparents and grandchildren have documented a variety of mediating factors. I incorporated these factors into the Family Demographic Survey. Demographic information regarding the grandparents' date of birth (age), age of entry into grandparenthood, gender, race, marital status, health status, socioeconomic status, and lineage connection to grandchild was requested on the survey. The date of birth (age) and gender of the custodial grandchildren were also requested. Demographic survey questions required either a response selection or production. A code for each response was developed to assist in data analysis.

#### The Family Needs Scale

The *Family Needs Scale* (FNS) (Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1987; 1988) measures the need for different resources and support in

the family's household. The scale is a self-report measure including 41 items rated on a 5-point scale ranging from almost never receiving this type of help (1) to almost always receiving this type of help (5). Dunst, Cooper, Weeldreyer, Snyder, and Chase (1987, 1988) used a principal components factor analysis to discern the factor structure of the scale. A nine-factor solution was determined. The factors included need for basic resources, specialized child-care, personal and family growth, financial and medical resources, child education, meal preparation, future child-care, household support, and financial budgeting. These factors were used in this study as dependent variables measuring grandparents' perception of their demands.

The reliability and validity of the FNS were established in a study of 54 parents of preschool- and elementary-aged children with disabilities or at risk for disabilities. According to Dunst (personal communication, January 2, 1994), the term parents was broadly defined to include any adult caregiver. Grandparents were among the "parents" participating in this study. Coefficient alpha, which measures internal consistency of the instrument, computed from the correlations among the 41 items was .95. The split-half reliability, corrected for length using the Spearman-Brown formula was .96. The criterion validity of the FNS indicated that the total scale score (reflecting the overall adequacy of resources) was significantly related to well-being ( $r = .42, p < .01$ ), decision-making ( $r = .40, p < .01$ ), and internal locus of control ( $r = .28, p < .05$ ).

Reliabilities for the factors were not established; therefore, reliability was determined on the data collected for this investigation. The FNS features a multiple-scored format, that is, there is no scored correct or incorrect or all-or-nothing system of response. For this reason a coefficient alpha rather than a Kuder-Richardson method was used to determine the internal consistency of each factor. The results are presented in Tables 1 through 3. Factor validity

was established by Dunst, Cooper, Weeldreyer, Snyder, and Chase (1987; 1988). Four of the seven factor scores--basic resources ( $r = .52, p < .01$ ), specialized child care ( $r = .52, p < .01$ ), financial and medical resources ( $r = .48, p < .01$ ), and financial budgeting ( $r = .35, p < .05$ )--were significantly related to well-being. Four of the seven factor scores--financial and medical resources ( $r = .45, p < .01$ ), future child care ( $r = .44, p < .01$ ), financial budgeting ( $r = .33, p < .05$ ), and household support ( $r = .30, p < .05$ )--were significantly related to decision-making. Two of the factor scores--specialized child care ( $r = .57, p < .01$ ) and financial and medical resources ( $r = .43, p < .01$ )--were significantly related to internal locus of control. Content validity of the instrument was substantiated through reviews by seven experts in the field. Suggestions of the expert reviewers were incorporated into the FNS (Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1987, 1988).

According to Dunst, Cooper, Weeldreyer, Snyder, and Chase (1987, 1988), the FNS was specifically developed for intervention purposes and to elicit family-identified needs. The responses on the FNS are used to prompt descriptions of the conditions that influence grandparents' assessment of their needs. The grandparents' responses help clarify their concerns and define their perceptions of their families' needs.

#### The Family Support Scale

The *Family Support Scale* (FSS) (Dunst, Jenkins, & Trivette, 1984; Dunst, Trivette, & Jenkins, 1988) is an 18-item self-report scale that measures the helpfulness of sources of support to families rearing young children. Support is defined as resources provided by other persons and groups to the children and families. The original scale included 18 items (plus 2 respondent-initiated items) rated on a 5-point scale ranging from not at all helpful (1) to extremely helpful (5). Respondents were instructed to leave blank any item that

did not apply to their family. The authors used a principal components factor analysis to discern the factor structure of the scale. Six factors were identified: informal kinship, spouse or partner support, social organizations, formal kinship, specialized professional services, and generic professional services. These factors were used in this study as dependent variables measuring grandparents' perception of their capabilities.

The reliability and validity of the FSS were examined in a study of 139 parents of preschool children with disabilities or at risk for disabilities. The definition of parent used in this study included grandparents, as well as other adults, who were the primary caregivers of the children (Dunst, personal communication, January 2, 1994). Internal consistency was established by computing a coefficient alpha from the average correlation among the 18 scale items ( $r = .77$ ). Coefficient alpha computed from the correlations of the 18 items with the total scale scores was .85. The split-half reliability corrected for length using the Spearman-Brown formula was .75 (Dunst, Jenkins, & Trivette, 1984; Dunst, Trivette, & Jenkins, 1988). Construct validity of the FSS was established through a principal components analysis. Content validity also was established. The total scale score for criterion validity of the FSS was consistently related to a number of parent and family outcomes, including personal well-being (average  $r = .28$ ,  $p < .01$ ), family unity integrity (average  $r = .18$ ,  $p < .01$ ), and parent perceptions of child behavior (average  $r = .19$ ,  $p < .05$ ). According to Dunst, Jenkins, and Trivette (1984) and Dunst, Trivette, and Jenkins (1988), the FSS is both reliable and valid.

Reliability data for each of the factors was not established; therefore, reliability was determined on the data collected for this investigation. The scale features a scoring format which has no scored correct or incorrect or all-or-nothing system of response. For this reason a coefficient alpha rather than a

Kuder-Richardson method was used to determine the internal consistency reliability of each factor. These results are in Tables 1 through 3.

The information provided on the FSS scale can be used to assess the number and quality of grandparents' support systems. The grandparents' responses provide a basis for further investigation into specific aspects of the help and lack of help they receive. The FSS can also be used to assess the success of interventions designed to address the grandparents' support status.

#### The Family Adaptation and Cohesion Evaluation Scales II

*The Family Adaptation and Cohesion Evaluation Scales (FACES) II* (Olson, Portner, & Bell, 1982; Olson, Bell, & Portner, 1991) is an unpublished, 30-item, self-report rating scale that measures family cohesion and family adaptability. The 5-point Likert-type response scale ranges from almost never (1) to almost always (5).

The 50-item version of the initial FACES II was administered to 2,412 individuals, including grandparents, in a national survey. On the basis of factor analysis and reliability analyses, the 50 items were reduced to 30 with 2 to 3 items for each of 14 content areas. The content areas include emotional bonding, family boundaries, coalitions, time, space, friends, decision-making, interests and recreations, assertiveness, leadership, discipline, negotiation, roles, and rules. Two domains, adaptability and cohesion, are represented by the 14 content areas. Family adaptability has to do with the extent to which the family system is flexible and able to change. Adaptability consists of two or three items each in the areas of assertiveness, leadership, discipline, negotiations, roles, and rules. Family cohesion has to do with the degree to which family members are emotionally bonded to one another. Cohesion includes two items each in the areas of emotional bonding, family boundaries, coalitions, time space, friends, decision-making, and interests and recreation.

Olson, Bell, and Portner (1991) reported that internal consistency of FACES II was  $r = .87$  for cohesion,  $r = .78$  for adaptability, and  $r = .90$  for the total scale. Test-retest reliability (short term) of the original 50 items measured at 4 to 5 weeks apart was  $r = .83$  for cohesion,  $r = .80$  for adaptability, and  $r = .84$  for the total scale. The authors reported the evidence of face validity and content validity as very good. Validity was also evidenced through correlational relationships. Correlations between the cohesion and adaptability scales ranged from  $r = .25$  to  $r = .65$ . Correlation with social desirability was  $r = .39$  for cohesion and  $r = .38$  for adaptability. The authors also reported a linear relationship providing good evidence of concurrent validity. Although the authors have established the reliability of the instrument, reliability for each factor was also determined using the data collected in this investigation (see Tables 3 through 5).

The four instruments together will measure grandparent and grandchildren characteristics and the grandparents' perceptions of their demands, capabilities, and adaptation. Listed in Table 6 are the factors each instrument is measuring.

### Description of the Procedure

#### Selection of the Sample

Initial contact letters explaining the purpose and procedures of the study were sent to each of Florida's 15 HRS districts and to 20 groups or organizations that work with custodial grandparents. Seven HRS districts and 2 grandparent groups responded favorably to my request and participated in the study. Names, mailing addresses, and phone numbers for all potential participants were solicited from these contacts. Potential participants were defined as grandparents who are raising grandchildren who are younger than 6 years of age and have not started kindergarten and who have disabilities or are

Table 6

Summary of Instrumentation

Family Needs Scale	Family Strengths Scale	FACES II	Grandparent And Grandchildren Information
Basic Resources	Informal Kinship	Family Cohesion	Grandparents' Age
Specialized Child Care	Spouse or Partner Support	Family Adaptation	Grandparents' Age of Entry
Personal and Financial Growth	Social organizations	Total Adaptation Scaled Score	Grandparents' Gender
Financial and Medical Resources	Formal Kinship		Grandparents' Race
Child Education	Professional Services		Grandparents' Marital Status
Meal Preparation	Total Support Score		Grandparents' Health Status
Future Child Care			Grandparents' Socioeconomic Status
Household Support			Grandparents' Lineage Connection
Financial Budgeting			Grandchildren's Age
Total Needs Score			Grandchildren's Gender

at risk for disabilities. Each contact was provided with the operating definitions of disability and at risk for disabilities to aid in their selection of potential respondent grandparents. The administrator of each participating HRS district designated a program from which to identify eligible families. Six of the participating districts identified potential families through their Children and Families Services programs. One district identified potential families through its



Children and Medical Services program. All but one participating district elected to disseminate surveys to all families which met the criteria established for participation. The district that did not disseminate to all families divided the total number of identified families in half, distributed an equal number of survey packets to each case worker, and asked them to use a random selection method to determine which families would receive the packets.

The organized grandparent support groups invited me to attend a regularly scheduled meeting to introduce myself and the study. Attendance at meetings is voluntary and the number and identity of grandparents are inconsistent. Grandparents who attended the meetings, met the criteria established for participation in the study, and volunteered to participate were provided with a survey packet.

#### Questionnaires and Questionnaire Selection or Development

The procedure for selection of the items for the demographic survey as well as selection of the scales was discussed previously in this chapter. After the items were developed for the demographic information survey, it was divided into a grandparent section and a grandchild section. The survey scales required some modification to match the targeted participants. The wording of the survey scales was adapted to fit the grandparent-grandchildren family. For example, the words "parent" and "children" were changed to "grandparent" and "grandchildren". Some questions were modified to clarify any ambiguity resulting from their wording. Questions about the need for multiple items, for example, were rewritten to ask about each item individually. The survey and cover letter were then piloted with two focus groups.

Each focus group consisted of six persons over the age of 60 years. Participants in each group were Caucasian males and females of middle socioeconomic status. Participants also represented a continuum of health and

educational status. The participants of each focus group were provided with copies of the cover letter and surveys. They were asked to read the materials and comment on the readability, format, clarity, and any other concerns they had regarding the materials. Information gathered from the focus group discussions was incorporated into the revised survey and cover letter.

#### Dissemination and Processing Procedures

Dissemination and processing procedures depended on confidentiality requirements of the individual HRS agencies and grandparent organizations. In all cases, because confidentiality prevented disclosure of potential participants' personal information, the HRS agency or grandparent organization assigned a contact person to oversee dissemination of surveys and reminder postcards. A packet for each potential participant, consisting of a cover letter, the survey instruments, and a self-addressed stamped return envelope was provided to the contact person (see Appendix B). Each packet was affixed with a postage stamp prior to dissemination to the contact person who affixed mailing labels for each potential participant. An identification code was marked on each survey packet, as well as on the outside of the mailing envelope, for tracking purposes. Contact persons were also provided with a list of the identification codes corresponding to the packets assigned to their district or organization. The contact persons were requested to affix a second mailing label, identifying recipients and their mailing addresses, next to the correct identification code for their packet.

A list of identification codes was maintained for the purpose of logging in surveys as they were returned. Four weeks after the initial mailing date, lists of returned surveys were given to district and organizational contacts. The contacts were provided with postage-paid reminder postcards to mail to recipients who had not returned their survey packets. One week after the first

reminder postcards were mailed, second reminder postcards were sent to survey recipients who had not returned their survey packets. The same procedure was followed with survey recipients to whom I had disseminated survey packets.

This procedure differed slightly when I met with the grandparent groups prior to dissemination. On those occasions, survey packets were distributed positively to the participants. However, I did not collect personal information from the recipients. I recorded only the identification numbers of the packets disseminated. The group facilitator recorded the names and addresses of the persons present, and the identification numbers of the packets disseminated to them, and acted as the contact person for all follow-up. Upon receipt of completed surveys, responses were coded and input for data analyses.

Due to the low return rate on the initial 200 surveys, additional surveys were disseminated to previously untapped HRS districts. The procedure of dissemination and tracking remained the same. However, the first reminder postcards were mailed after 10 days. Rather than sending second reminder postcards, a second copy of the survey and a new cover letter (see Appendix B) were mailed 15 days after the initial mailing. An additional 62 survey packets with the second cover letter were also provided to one HRS district, at their request, to send to all recipients who had not responded to the first mailing.

#### Treatment of the Data

Data analysis was divided into two phases. First, data were analyzed to yield descriptive statistics for independent and dependent variables. Second, appropriate statistical analyses were conducted for each hypothesis. Two decision rules were developed of use with the data. First, significance was set

at the  $p < .05$  level. Second, Hypotheses were rejected if regression coefficients were significant.

Descriptive statistics for all variables under investigation included frequencies and percentages for categorical variables and means and standard deviations for continuous variables. For the purposes of descriptive analysis of the obtained scaled scores for the FNS and the FACES, the blank or 0 responses were not included in calculation of the means, modes, or standard deviations. Modes were obtained by identifying the most commonly occurring average rather than the most commonly occurring response. Correlations among independent variables as well as between independent and dependent variables were obtained. Categorical data were coded with a number value in order to run analysis (see Appendix C). Correlations assisted in summarization of the relationships that exist between variables. Correlations also assisted in identifying any multicollinearity existing among independent variables. If the intercorrelations between any of the independent variables were .80 or higher, these factors were combined into a single variable. If the intercorrelations among the independent variables were less than .80, these factors were retained as separate variables.

Hypothesis 1 examined the relationship between the grandparents' perceptions of their demands and grandparents' and grandchildren's characteristics. (Note: For more specific information regarding the number and identity of variables for each hypotheses, refer to Table 6: Summary of Instrumentation) This relationship was investigated through multiple regression techniques with the independent variables predicting the families' demands. The total needs score (TNS) acted as the dependent variable and the grandparent and grandchild factors were the independent variables.

The relationship between the grandparents' perception of their capabilities and grandparent and grandchild characteristics was examined in Hypothesis 2. This relationship was also investigated through multiple regression techniques with the independent variables predicting the families' capabilities. The independent variables were the grandparent and grandchild factors and the dependent variable was the total support score (TSS).

The relationship between grandparent and grandchild characteristics and the grandparents' perception of their adaptation was examined by Hypothesis 3. Multiple regression techniques were used to investigate this relationship. The grandparent and grandchild characteristics were the independent variables predicting family cohesion and family adaptation. The total adaptation score (TASS) was used as the dependent variable.

Hypothesis 4 examined the relationship between the grandparents' perceptions of their demands and their capabilities. Simple bivariate regression techniques were used to investigate the relationship of family demands and family capabilities. The variables to be included in the regression model were determined by the data resulting from the correlations and previously completed regression analyses. The total support score (TSS) was used as the independent variable and the total needs score (TNS) was used as the dependent variable during the analysis.

Hypothesis 5 examined the relationship between the grandparents' perceptions of their demands and adaptation. This relationship was investigated through simple bivariate regression techniques. The variables to be included in the regression model were determined by the data resulting from the correlations and previously conducted regression analyses. The total needs score (TNS) was used in the regression model to predict the total adaptability score (TASS).

Hypothesis 6 examined the relationship between the grandparents' perceptions of their capabilities and adaptation. This relationship was investigated through simple bivariate regression techniques. The variables to be included in the regression model were determined by the data resulting from the correlations and previously conducted simple bivariate regression analyses. The total support score (TSS) was used in the simple bivariate regression model to predict the total adaptability score (TASS).

A composite of the analyses of the six hypotheses creates a model of the relationships between the families' demands, capabilities, adaptability, and grandparent and grandchildren characteristics. As pictured in Figure 5, the analytic model illustrates the relationships between the grandparents' and grandchildren's characteristics, the families' demands, capabilities, and adaptation.

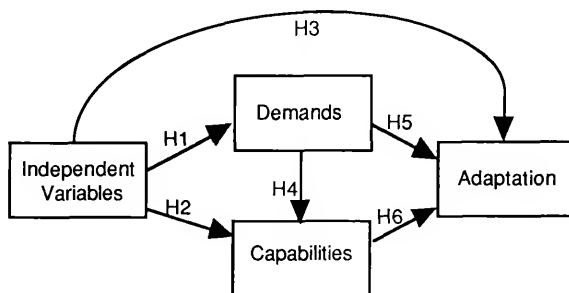


Figure 5. Analytical Model

The effects between these variables were also established through analysis of the data for each hypothesis. Results of the data analyses are presented in the next chapter.

## CHAPTER FOUR RESULTS OF THE STUDY

### Introduction

The purpose of this study was two-fold. To investigate the relationship between the demands, capabilities, and adaptation of grandparents raising young grandchildren with disabilities or at risk for disabilities and, to make inferences about Family Systems Theory and the operational Family Adjustment and Adaptation Response (FAAR) Model in regards to a nontraditional family structure--the custodial grandparent and grandchild family. Other key variables that have received extensive study in the area of the relationship between grandparents and grandchildren were also investigated as to their relationship with the custodial grandparents' demands, capabilities, and adaptation. To address these purposes, four major questions were posed. The first question concerned whether custodial grandparents' age, age of entry into grandparenthood, gender, race, marital status, health status, socioeconomic status, or lineage connection to the grandchild, or the grandchild's age or gender affect the custodial grandparents' perception of the demands they experience. Therefore, I sought to determine what demands grandparents were experiencing and their relationship with specific grandparent and grandchild factors. The second question concerned whether the custodial grandparent or the grandchild factors have an effect on custodial grandparents' perception of their capabilities. This question included the investigation of the grandparents' perception of their capabilities, as well as grandparent and grandchild factors that affected these capabilities. The third

question concerned whether the custodial grandparent or the grandchild factors have an effect on the custodial grandparents' perception of their adaptation. To answer this question, I investigated the adaptation of families headed by custodial grandparents as well as grandparent and grandchild factors that affected their adaptation. The final question explored the relationship between custodial grandparents' perceptions of their demands, capabilities, and adaptation.

In this chapter, the results of this study are presented in three major sections. In the first section I will present data describing the sample, and in the second, the scaled scores for the *Family Needs Scale*, the *Family Support Scale*, and the *Family Adaptation and Cohesion Evaluation Scales II*. In the third section I will present the results of the statistical analyses. A final section summarizes the results of the study.

#### Description of the Sample

A total of 377 survey packets was disseminated, of which 135 (37%) were returned. After eliminating surveys that could not be scored due to incomplete responses or ineligibility as a result of age of child or relationship to the child, a sample of 93 (25%) grandparents was obtained. The ages of grandparents ranged from 35 years to 72 years, with a mean age of 50 years and a mode of 49 years. The age of the grandparents when the custodial grandchildren were born (age of entry) for the reported grandchildren ranged from 33 years to 67 years, with a mean age of entry of 47 years and a mode of 42 years. Sixty-two (67%) of the grandparents were Caucasian; 29 (31%) were African-American; and 2 (2%) were Hispanic. The marital status of the grandparents was as follows: 53 (57%) were married; 23 (25%) were divorced or separated; 7 (7%) were widowed; 3 (3%) were remarried; 4 (4%) were living with a partner; and 3 (3%) were single. Seventy-nine (85%) of the respondents



were grandmothers, and 14 (15%) were grandfathers. Sixteen (17%) of the grandparents reported their health as being excellent, 46 (50%) as being good, 27 (29%) as being okay, and 4 (4%) reported their health as being poor.

Eighteen (19%) of the grandparents' reported their family's annual income as less than \$5,000, 14 (15%) as \$5,000-\$9,999, 20 (22%) as \$10,000-\$19,999, 18 (19%) as \$20,000-\$29,999, 11 (12%) as \$30,000-\$40,000, and 12 (13%) as reported their family's annual income as over \$40,000. Twenty-seven (29%) of the grandparents were raising their sons' children, 58 (62%) were raising their daughters' children, and 8 (9%) were raising children with another lineage connection (step-grandchildren).

The grandchildren's ages ranged from less than a year up to 6 years.

Table 7 presents the information on grandchildren's age.

Table 7

Grandchildren's Ages by Frequency and Percent

Grandchildren's Age	Frequency	Percent
birth-6 months	1	1
6-18 months	15	16
18-30 months	11	12
30-42 months	16	17
42-54 months	26	28
54-66 months	21	23
66-72 months	3	3

Forty-six of the grandchildren (50%) were grandsons, and 47 (50%) were granddaughters. Twenty-five ( 28%) of the grandchildren had a diagnosed

disability, while 64 (72%) had no diagnosis but were considered at risk. Ten (11%) of the grandchildren with a disability were diagnosed developmentally delayed, 2 (2%) had vision problems, 2 (2%) had physical disabilities, 7 (8%) had emotional/behavior disabilities, 1 (1%) had a hearing impairment, and 5 (5%) had learning disabilities. Another (1%) grandchild had hyperactivity, 1 (1%) was diagnosed with cerebral palsy, and 1 (1%) had problems associated with premature birth. Three (3%) grandchildren had speech problems, 4 (4%) had respiratory problems, 1 (1%) had neurological involvement, and 2 (2%) had heart disorders. Two (2%) grandchildren had problems associated with sexual abuse, and 3 (3%) had problems associated with prenatal exposure to cocaine and other drugs.

Open-ended questions were used to investigate the reason for the grandparents' custody of the grandchildren. The primary reason was the alcohol and drug use of the grandchildren's biological parents. Many grandparents reported that the custodial grandchild had been prenatally exposed to this substance abuse. This prenatal exposure to substance abuse is a factor that places the custodial grandchild at risk for disabilities. It is difficult to compare the demographics of this sample to the population of custodial grandparents as there is limited demographic information available of this population as a cohort.

#### Description of Scaled Scores

The descriptive statistics for the FNS, the FSS, and the FACES II are reported in the following section. The mean scaled scores of the factors for each instrument were correlated to determine the relationship among the factors and the total scaled score. Information from the Pearson Product Moment correlations is also reported in the following section. A decision rule

established significance at the  $p < .05$  level. This rule was applied to all relevant analyses.

### Family Needs Scale Scores

The number of items per domain, mean, standard deviation, and  $\pm$  one standard deviation range for the average total scores of each domain and the total needs score for the FNS are presented in Table 8.

Table 8

### Descriptive Statistics for the Family Needs Scale

Factor	Number of Items	$\pm 1$ SD	Mean	Standard Deviation
Basic Resource	16	1.52 - 4.36	2.94	1.42
Specialized Child Care	11	1.54 - 3.96	2.75	1.21
Personal and Family Growth	6	1.29 - 3.39	2.34	1.05
Financial and Medical Resource	7	1.73 - 4.33	2.98	1.25
Child Education	2	1.20 - 4.16	2.68	1.48
Meal Preparation	3	1.58 - 4.80	3.19	1.61
Future Child Care	2	1.18 - 4.06	2.62	1.44
Household Support	1	1.08 - 4.16	2.62	1.54
Financial Budgeting	1	0.87 - 3.89	2.38	1.51
Total Needs Score	49	1.66 - 4.00	2.83	1.17

Respondents were asked "To what extent does your family get these types of help?" Any item left blank was scored as 0 = not applicable and was not used in calculating the mean and standard deviation. The response codes and definitions are as follows: 1 = almost never, 2 = seldom, a few times, 3 = sometimes, half the time, 4 = often, and 5 = almost always. Dunst, Cooper, Weeldreyer, Snyder, and Chase (1987) stated that a score of 0, 1, or 2 indicated the need is not being adequately met. The readers' attention is directed towards the  $\pm$  one standard deviation range of scores, representing the heterogeneity of this sample. Some grandparents receive an adequate amount of assistance to meet their needs while others do not receive adequate assistance to meet their needs.

Basic resources (BR) is a measure of the grandparents' need for assistance with furnishings, clothing, child care, health care, transportation, food, utilities, and employment. The mean score of 2.94 indicates that grandparents perceive the assistance they receive in meeting these needs to be adequate about half the time. In open-ended questions the majority of grandparents noted they needed assistance in providing toys, clothing, day care or baby-sitting, and adequate living space for their grandchildren.

The specialized child care (CC) domain measures the grandparents' need for assistance with specialized dental and medical care, respite care, adapted equipment, and someone to talk to about their grandchild. The mean score of 2.75 indicates that grandparents are experiencing some difficulty adequately meeting these needs. The grandparents' response to the open-ended questions indicate they have little if any time to spend with other family members or by themselves due to their lack of respite care for their grandchildren. Custodial grandparents also indicated a lack of contact with or knowledge of other grandparents who are also raising their grandchildren.

Personal and family growth (PFG) measures the grandparents' need for assistance with doing things together as a family, educational opportunities, family travel and vacations, and saving money for the future. The mean score of 2.34 indicates that grandparents' needs in this area are seldom adequately met. It should be noted that this domain received the lowest mean of all the domains. On the open-ended questions, some grandparents indicated they are performing multiple roles: working outside the home, caring for their spouse, children or other grandchildren, as well as their young grandchildren with disabilities or at risk for disabilities. Grandparents also expressed concern over their shrinking savings and retirement accounts and their inability to save for the future.

The domain of financial and medical resources (FMR) measures the grandparents' need for assistance in paying for special child necessities, money for basic necessities, and adequate family health care. As indicated by the mean score of 2.98, grandparents are experiencing difficulty adequately meeting these needs about half the time. It should be noted that all respondents to this survey were recipients of some assistance from Health and Rehabilitative Services (HRS). Responses to the open-ended questions indicate that the majority of the grandparents are receiving no financial assistance and little physical assistance from the custodial grandchildren's parents. Many of the grandparents noted that the amount of money received from social services was not adequate to meet the expense of raising their grandchildren, especially child care.

Child education (CE) measures the grandparents' need for assistance with adequate current and future educational placements, child care, and child therapy. The mean score of 2.68 shows that grandparents sometimes experience difficulty adequately meeting these needs. Few grandparents

commented on this domain in their responses to open-ended questions other than to say they could not afford to put their grandchildren in day care.

The meal preparation (MP) domain measures the grandparents' needs regarding time to cook meals, help feeding the grandchild, and adapted equipment for meals. The mean score of 3.19, which was the highest mean of all the domains, shows that the custodial grandparents perceive that these needs are being adequately met about half the time. Grandparents did not comment on meal preparation in the open-ended questions.

Future child care (FCC) measures the grandparents' need for a assistance in respite care, child care, and addressing the grandchild's future vocation. Grandparents perceive that their needs regarding future child care are sometimes adequately met ( $M=2.62$ ). Responses on open-ended questions indicated that many grandparents were concerned for their grandchildren's safety, especially if custody were returned to the parent(s). Grandparents also were concerned over what would happen to their grandchildren when the grandparents were no longer able to care for them.

Household support (HS) measures the grandparents' need for assistance with completing chores, repairs, and home improvement. The mean score of 2.62 indicates that grandparents' perception is that they sometimes experienced difficulty adequately meeting these needs. Grandparents did not comment in the open-ended questions on this area of need.

The financial budgeting (FB) domain, which received the second lowest mean score, measures the grandparents' need for assistance with budgeting money. The perception of the grandparents is that they are experiencing some difficulty adequately meeting these needs, as indicated by the mean score of 2.38. Grandparents did not comment on financial budgeting in their responses to open-ended questions.

The total needs score indicates the grandparents' perception of the amount of assistance they receive in meeting their needs. The mean score of 2.83 indicates that grandparents are having their needs adequately met about half the time. The majority of grandparents commented in the open-ended questions on the legal restrictions placed on them that interfere with their meeting their needs. Grandparents reported that they do not know when or if the courts will return custody to the grandchildren's parent(s) and that this uncertainty hampers their ability to plan for the future and to address their needs adequately.

Correlations were used to help determine which demand variables to include in the analyses of hypotheses and are presented in Table 9. Significant positive relationships were found among all but eight of the domains. The strength of the relationships between the TNS and the remaining FNS domains ranged from moderate to strong, with the exception of the relationship between TNS and child care which was weak. These findings, in conjunction with the coefficient alphas for these data and the recommendations of Dunst, Cooper, Weeldreyer, Snyder, and Chase (1987, 1988), resulted in the use of the total needs score as the dependent variable. It is interesting to note that the eight nonsignificant relationships were between the specialized child care domain and the remaining seven domains. It is unclear whether this difference is a phenomena of this sample, of custodial grandparents in general, or the items in the domain.

Table 9

Correlation Matrix for the Family Needs Scale

	BR	CC	PFG	FMR	CE	MP	FCC	HS	FB	TNS
BR	1.000									
CC	0.079*	1.00								
PFG	0.391	0.004*	1.000							
FMR	0.794	0.179*	0.530	1.000						
CE	0.758	0.150*	0.655	0.712	1.000					
MP	0.926	0.074*	0.434	0.827	0.745	1.000				
FCC	0.536	0.111*	0.659	0.682	0.755	0.580	1.000			
HS	0.466	0.146*	0.700	0.676	0.568	0.517	0.689	1.000		
FB	0.495	-0.082*	0.457	0.577	0.485	0.459	0.450	0.537	1.000	
TNS	0.931	0.204	0.638	0.903	0.866	0.917	0.733	0.683	0.592	1.000

Note. \* Not significant

BR=Basic Resources

CC=Specialized Child Care

PFG=Personal and Family Growth

FMR=Financial and Medical Resource

CE=Child Education

MP=Meal Preparation

FCC=Future Child Care

HS=Household Support

FB=Financial Budgeting

TNS=Total Needs Score

Family Support Scale Scores

Reported in Table 10 are the number of items, mean, standard deviation, and  $\pm$  one standard deviation range for the average total scaled scores of each domain and the total support score for the FSS.

Grandparents were asked "How helpful has each source been in terms of raising your grandchild?" A score of 0 = not available was assigned to items left blank. Scores of 0 were not included in calculating the means or standard



deviations. The instrument scale scores are 1 = not at all helpful, 2 = helpful a few times, 3 = helpful half the time, 4 = very helpful, and 5 = extremely helpful. The mean score and  $\pm$  one standard deviation range of scaled scores are reported for each factor of the FSS, giving an indication of the heterogeneity of the sample. Some custodial grandparents perceived their resources as not at all helpful while others perceived them to be very helpful.

Table 10

Descriptive Statistics for the Family Support Scale

Factor	Number of Items	$\pm$ 1 SD	Mean	Standard Deviation
Informal Kinship	6	1.48 - 3.66	2.57	1.09
Spouse or Partner Support	4	1.35 - 4.09	2.72	1.37
Social Organizations	5	1.28 - 3.84	2.56	1.28
Formal Kinship	2	1.23 - 3.93	2.58	1.35
Professional Services	5	1.66 - 4.14	2.90	1.24
Total Support Score	22	1.71 - 3.71	2.71	1.00

The informal kinship domain (IK) measures the helpfulness of the grandparent's friends, spouse's or partner's friends, grandparent's children, other parents and grandparents, and the grandparent's church. The mean score of 2.57 indicates that grandparents perceive their informal kinship network to be helpful a few times to half the time. In response to open-ended questions, many grandparents reported that their faith or religion was a source of strength.

Spouse or partner support (SPS) measures the perceived helpfulness of the grandparent's spouse or partner, spouse's or partner's parents, and spouse's or partner's relatives. Custodial grandparents' perceived their spouses or partners to be helpful, but not very helpful ( $M=2.72$ ). In open-ended questions, some grandparents commented on the helpfulness of their spouses, while others commented on the strain put on their relationship with their spouse. No comments were made regarding the spouse's other relatives.

The social organizations (SO) domain measures the perceived helpfulness of social groups and clubs, parent and grandparent groups, school and day care centers, and the grandparent's co-workers. The mean score of 2.56, which was the lowest mean score, indicates that the social organizations are helpful a few times to about half the time. Grandparents noted, in response to open-ended questions, that they were not aware of grandparent support groups.

Formal kinship (FK) measures the perceived helpfulness of the grandparent's own relatives including the grandparent's parents. This domain received the second lowest mean score. Custodial grandparents perceived their own relatives to be somewhat helpful ( $M=2.58$ ). Responses made by many custodial grandparents to open-ended questions indicated that they do not receive assistance from their own relatives, especially the parent of the custodial grandchildren.

The professional services (PS) domain measures the perceived helpfulness of early intervention programs, professional helpers, the family or grandchild's physician, and professional agencies. The mean score of 2.90, which was the highest mean score, indicates that grandparents perceived specialized as well as generic professional services to be helpful about half the time. That grandparents do not perceive professional services to be very

helpful is reflected in responses to open-ended questions. Many grandparents reported a lack of financial, legal, and emotional support from the HRS and the legal system. The custodial grandparents indicated much uncertainty and anger connected to HRS and the legal system.

The total support score (TSS) represents the grandparents' perception of the overall number and quality of capabilities available to them. Overall, custodial grandparents' perception was that they received some help in meeting their families' needs ( $M=2.71$ ).

To determine whether the number of dependent capability variables might be reduced, thus simplifying the analyses, the Pearson Product Moment correlations among the domains of the FSS were examined. Correlation coefficients are reported in Table 11.

Table 11

Correlation Matrix of the Family Support Scale

Domain	Domain					
	Informal Kinship	Spouse or Partner Support	Social Organizations	Formal Kinship	Professional Services	Total Support Score
Informal Kinship	1.000					
Spouse or Partner Support	0.703	1.000				
Social Organizations	0.541	0.573	1.000			
Formal Kinship	0.660	0.507	0.275	1.000		
Professional Services	0.486	0.398	0.570	0.357	1.000	
Total Support Score	0.879	0.804	0.786	0.698	0.750	1.000

Note. Correlations are significant at the  $p < .05$  level.

The relationships between each FSS domain score and the total support score were significant. Significance indicates that although the variables are not measuring the same construct, they are measuring similar constructs. The strength of the relationships between the TSS and the remaining FSS domains ranged from moderate to strong. The relationships among the remaining domains were also significant, positive, and moderate to strong, except for the weak relationship between formal kinship and social organizations. These findings, in conjunction with the coefficient alphas for these data and the recommendations of Dunst, Trivette, and Jenkins (1984, 1988), resulted in the use of the total support score as a dependent variable.

#### Family Adaptation and Cohesion Evaluation Scale II Scores

The number of items, mean, standard deviations, and  $\pm$  one standard deviation range for the average total scores of each of the domains and the total adaptation scaled score of the FACES II are reported in Table 12.

Table 12

#### Descriptive Statistics for the Family Adaptation and Cohesion Evaluation Scale II

Factor	Number of Items	$\pm$ 1 SD	Mean	Standard Deviation
Family Cohesion	16	33.12 - 56.78	45.05	11.93
Family Adaptation	14	26.67 - 50.07	38.37	11.70
Total Adaptation Scaled Score	30	60.86 - 105.98	83.42	22.56

Grandparents were asked "How frequently does the described behavior occur in your family?" A score of 0 = not applicable was assigned to items left blank and was not included in calculating the mean and standard deviation.

The code for other responses is as follows: 1 = almost never, 2 = once in awhile, 3 = sometimes, 4 = frequently, and 5 = almost always. However, Olson, Bell, and Portner (1991) have established a scoring and interpretation protocol, the Circumplex Model, which is used to score and interpret the FACES II responses. After obtaining the total cohesion and the total adaptability scores, the corresponding 1 - 8 score for each dimension was located on the "Linear Scoring and Interpretation" guidelines. Appendix D provides the scoring and interpretation guidelines for the Circumplex Model. The family type score (1 - 8) was obtained by adding the 1 - 8 cohesion and adaptability scores and dividing by 2. The interpretation of the family type score (1 - 8) was also indicated on the scoring and interpretation guidelines.

The Circumplex Model has four levels of family cohesion ranging from extreme low cohesion to extreme high cohesion. Cohesion domain scoring and interpretation is as follows: means of 1 and 2 are disengaged family types, 3 and 4 are separated family types, 5 and 6 are connected family types, and 7 and 8 are enmeshed family types.

There are also four levels of family adaptability within the Circumplex Model. These levels also range from extreme low to extreme high adaptability: rigid, structured, flexible, and chaotic. Adaptability domain scores of 1 and 2 are interpreted as rigid family types, 3 and 4 as structured family types, 5 and 6 as flexible family types, and 7 and 8 are interpreted as chaotic family types.

By combining the four levels of cohesion and the four levels of adaptability, the Circumplex Model identifies 16 distinct family types. Four of these 16 types are considered moderate types on both the cohesion and adaptability dimensions. These four are labeled as balanced family types. Eight types are considered extreme on one dimension and moderate on the other dimension. These family types are labeled as mid-range types. The

remaining four types are considered extreme on both dimensions and are labeled as extreme family types. The scoring and interpretation for the total adaptation score is as follows: 1 and 2 are extreme family types, 3 through 6 are mid-range family types, and 8 and 9 are balanced family types.

Family cohesion can be explained as the emotional bonding that family members have toward one another. Dimensions of family cohesion include emotional bonding, boundaries, coalitions, time, space, friends, decision-making, interests, and recreation. According to Olson, Bell, and Portner (1991), there are four levels of family cohesion ranging from very low cohesion (disengaged) to low to moderate cohesion (separated) to moderate to high cohesion (connected) to very high cohesion (enmeshed). The mean total cohesion score of 45.05 for the FACES II is scored as a 2 on the Linear Scoring guide. This score indicates that the families of the custodial grandparents in this study have very low cohesion and that they are within the disengaged range. A family in the disengaged range may have little closeness, lack loyalty, and have highly independent members. In disengaged type family systems, family members may "do their own thing", with limited attachment or commitment to their family (Olson, 1993). However, the standard deviation indicates a range of cohesion responses that vary from very low cohesion to low to moderate cohesion. According to Olson (1993), such family systems may have some emotional separateness, but not necessarily to the extreme degree. Time apart may be more important to family members in this range but there are some times together, some joint decision making, and some marital support.

Family adaptation is the ability of a family system to change its power structure, role relationships, and relation rules in response to situational and developmental stress. Dimensions of family adaptation include assertiveness, control, discipline, negotiation style, role relationships, and relationship rules.

Olson, Bell, and Portner (1991) noted four levels of family adaptation, ranging from extreme low adaptability (rigid) to moderately low adaptability (structured) to moderately high adaptability (flexible) to extreme high adaptability (chaotic). The mean family adaptation score (38.37) for the FACES II is scored as a 2 on the Linear Scoring guide. This score indicates that the families of the custodial grandparents in this study have extremely low adaptability and may be functioning in the rigid range. Olson (1993) noted that rigid families may seldom change roles, may have strict discipline, authoritarian leadership, and too little change. A rigid relationship exists when one family member is in charge and is highly controlling. Families in the rigid range tend to have limited negotiations with most decisions imposed by the leader. The family roles are strictly defined, and the rules do not change in rigid families. The  $\pm$  one standard deviation range of responses, however, illustrated that custodial grandparents' family adaptability varied from extremely low adaptability to moderately high or flexible adaptability. Families in this range may have an equalitarian leader with democratic decision making (Olson, 1993). Flexible families may negotiate openly and actively include the children. Roles in flexible family types may be shared, there may be fluid change when necessary, and rules can be changed and may be age-appropriate.

The family type is derived from the average of the cohesion and adaptability linear scores (family type = 2). This score indicates that the families of the grandparent respondents in this study may be functioning in the extreme family type range. Families in the extreme range are on the extreme end of both dimensions (cohesion and adaptability) and, according to Olson (1993) are viewed as problematic. Extreme family types may not be able to balance their independence and connectedness, their flexibility and rigidity. The  $\pm$  one standard deviation range of responses indicated in cohesion and adaptability

would also be evident in extreme family types. Therefore, custodial grandparents' family type range from extreme to moderately balanced family types. Olson (1993) noted that moderately balanced family types may be able to experience and balance the extremes of cohesion and adaptability. Moderately balanced family types are viewed as optimally functioning.

To determine whether the number of dependent adaptation variables might be reduced, thus simplifying the analyses, the Pearson Product Moment correlations among the domains of the FACES II were examined. The correlations are reported in Table 13. The strong, significant relationship between the TASS and family cohesion and family adaptation and the coefficient alphas for these data resulted in the use of the total adaptation score as the dependent variable.

Table 13

Correlation Matrix of the FACES II by Domain

Domain	Domain		
	Family Cohesion	Family Adaptation	Total Adaptation Scaled Score
Family Cohesion	1.000		
Family Adaptation	0.433	1.000	
Total Adaptation Scaled Score	0.839	0.851	1.000

Note. Correlations are significant at the  $p < .05$  level.

Analysis of the Data

In this section I present information regarding the analysis of the data. First, I will present information concerning the relationships among the grandparent and grandchild variables. Next, I will present information regarding the analysis of the hypotheses.



### Relationships among Grandparent and Grandchild Variables

The relationships among the grandparent and grandchild variables were explored to determine whether the number of independent variables might be reduced, thus simplifying the analyses. First the relationships between continuous variables were investigated, followed by the relationships between categorical and continuous variables and the relationships between categorical variables.

Relationships between continuous variables Pearson Product Moment correlations were used to investigate the relationships between pairs of continuous independent variables--grandparents' age (GPA), age of entry into grandparenthood (AE) for the grandchildren targeted by this investigation, and grandchildren's age (GCA). This correlation matrix is presented in Table 14.

Table 14

#### Correlation Matrix of the Continuous Independent Variables

Variable		Variable	
	Grandparent Age	Age of Entry into Grandparenthood	Grandchild Age
Grandparent Age	1.00	0.972**	0.096
Age of Entry into Grandparenthood		1.00	-0.072
Grandchild Age			1.00

Note. \*\*Significant at the  $p < .05$  level.

The correlation between grandparent age and age of entry into grandparenthood for the grandchild who is the focus of this study is significant, positive, and strong. The correlations between grandparent's age and grandchildren's age and grandchildren's age and age of entry were not

significant. For this reason GPA and GCA were kept as separate independent variables.

#### Relationship between categorical and continuous variables

The relationships between the categorical independent variables-- grandparents' gender, race, marital status, health status, socioeconomic status, lineage connection to the grandchild, and grandchild's gender -- and the three continuous independent variables were also investigated. According to Pedhazur (1982), it is possible to use categorical variables in regression analysis but it is first necessary to code such variables.

Dummy coding is the simplest such method. Therefore, dummy codes were created for each categorical variable, and a Pearson Product Moment correlation was obtained for the relationship between the continuous variables and the categorical variables. A number of vectors were generated, such that, in any given vector, membership in a given group or category was assigned a 1, while nonmembership in the category was assigned a 0. For example, lineage connection is a categorical independent variable with three categories: son's child, daughter's child, and other. A dummy code was established in which son's child was assigned a 1 in category #1, and a 0 in category #2. Daughter's child was assigned a 0 in category #1 and a 1 in category #2. This leaves "other" with an assignment of 0 in both categories. The number of vectors assigned to a variable is always the number of groups or categories within the variable minus 1.

In the event that responses to some categories were too few to do a meaningful analysis, the response categories were combined. For this reason, the categorical independent variable, grandparent race, was divided into Caucasian and minority. The categorical independent variable, grandparent health status, became GPHS-ex/good, representing the excellent and good

responses, and GPHS-ok/poor, representing the okay and poor responses. Grandparent marital status became GPMS-married, representing the married, remarried, and living with partner respondents, and GPMS-single, representing the divorced, widowed, and single respondents. Lineage connection became LC-son's, representing the son's child, LC-daughter's, representing the daughter's child, and LC-other, representing another lineage connection. The results of this investigation are presented in Table 15.

Table 15

Correlation Matrix of the Categorical by Continuous Independent Variables

	Grandparent Age	Grandchild Age
Grandparent Gender	0.117	0.162
Grandparent Race	-0.096	0.034
Grandparent Marital Status-married	-0.200	-0.078
Grandparent Health Status-ex/good	-0.263**	-0.137
Socioeconomic Status	-0.168	0.020
Lineage Connection-son's	-0.028	-0.028
Lineage Connection-daughter's	-0.203	0.069
Grandchild Gender	-0.083	0.035

Note. \*\* Significant at the  $p < .05$  level

Grandparents' health status-ex/good and grandparents' age were significantly related. This relationship was negative, indicating that as grandparents aged the quality of their health decreased. I concluded that the categorical and continuous independent variables were not measuring the

same or similar constructs. Therefore, the categorical independent variables grandparents' gender, race, marital status, health status, socioeconomic status and lineage connection to the grandchildren, as well as grandchildren's gender were retained as independent variables for the purpose of analysis of Hypotheses 1, 2, and 4.

#### Relationship between categorical variables

The relationships between pairs of categorical independent variables including grandparents' gender, race, marital status, health status, socioeconomic status, and lineage connection to the grandchild, as well as grandchild's gender--was explored using chi-square ( $\chi^2$ ) analysis. The results of this investigation are presented in Table 16.

Six of the relationships were significant: grandparents' gender and lineage connection to the grandchild, grandparent's gender and grandchild's gender, grandparents' race and socioeconomic status, grandparents' marital status and race, grandparents' marital status and socioeconomic status, and grandparents' lineage connection to the grandchild and socioeconomic status. Investigation into the relationships between categorical independent variables also revealed that 86% of the grandfathers were raising grandsons while the grandmothers were equally likely to be raising grandsons (47%) or granddaughters (43%).

This investigation revealed several interesting relationships. One is that a larger proportion of the minority grandparents have an annual family income on the lower end of the range while a larger proportion of the Caucasian grandparents have an annual family income on the higher end of the range. Another interesting relationship is that 73% of the Caucasian grandparents were either married or living with a partner while only 48% of the minority

Table 16

Relationship Between the Categorical Independent Variables

	df	$\chi^2$
Grandparent Gender x Grandparent Health Status	1	1.004
Grandparent Gender x Socioeconomic Status	5	3.438
Grandparent Gender x Lineage Connection	2	8.666**
Grandparent Gender x Socioeconomic Status	5	2.499
Grandparent Gender x Grandchild Gender	1	8.665**
Grandparent Race x Grandparent Gender	1	2.060
Grandparent Race x Grandparent Health Status	1	1.548
Grandparent Race x Socioeconomic Status	5	21.325**
Grandparent Race x Lineage Connection	2	4.597
Grandparent Race x Grandchild Gender	1	0.020
Grandparent Marital Status x Grandparent Gender	1	0.391
Grandparent Marital Status x Grandparent Race	1	5.284**
Grandparent Marital Status x Grandparent Health Status	1	0.211
Grandparent Marital Status x Socioeconomic Status	5	15.921**
Grandparent Marital Status x Lineage Connection	2	1.966
Grandparent Marital Status x Grandchild Gender	1	0.050
Grandparent Health Status x Socioeconomic Status	5	3.038
Grandparent Health Status x Lineage Connection	2	0.071
Lineage Connection x Socioeconomic Status	10	27.833**
Grandchild Gender x Grandparent Health Status	1	0.086
Grandchild Gender x Socioeconomic Status	5	3.659
Grandchild Gender x Lineage Connection	2	0.599

Note. \*\* Significant at  $p < .05$  level

grandparents were married or living with a partner. The grandparents who were married, remarried, or who lived with a partner had a higher annual family income than did the grandparents who were divorced, widowed, or single. Finally, grandparents raising their sons' children had a higher income than did grandparents raising their daughters' children.

Although the chi-squares of six relationships between categorical variables were significant the strength of the relationships was not strong, I concluded that these variables were not measuring the same or similar constructs. Therefore, all variables were retained as independent variables for the purpose of analysis of Hypotheses 1, 2, and 3.

### Hypothesis Testing

In this section, the results of the statistical analyses are presented by hypothesis. First the correlational data between individual grandparent and grandchild factors and the FNS, the FSS, and the FACES are presented. It should be noted that the correlational model does not distinguish between an independent or dependent variable (Pedhazur, 1982).

Rather than assisting in explaining or predicting relationships, the correlational coefficients represent the degree of relation between the variables. In order to predict the relationship between independent and dependent variables the regression model was used. The regression model is most directly related to explanation and prediction of phenomena (Pedhazur, 1982). Each hypothesis is discussed in terms of the correlational relationship between the variables and the regression analysis of the predictive use of the relationship.

Two types of regression tests were used in the analysis of the hypotheses. A bivariate regression test was run for Hypotheses 4, 5, and 6, as these hypotheses had a single independent and dependent variable. Multiple

regression tests were run for Hypotheses 1, 2, and 3, as these hypotheses had multiple independent variables and a single dependent variable.

A regression source table is presented for each hypothesis. The source table presents the data resulting from the analysis of the hypothesis. For example, in Hypothesis 1 the relationship between the nine grandparent and grandchild factors, as a whole, and the custodial grandparents' needs were investigated. The source table presents the information on the predictability of the dependent variable, demands, based on the independent variables in total. The source table does not present information on the relationship between individual grandparent or grandchild factors and the custodial grandparents' needs.

A parameter table is also presented for each multiple regression analysis conducted showing the partial regression coefficient for each independent variable. The parameter table is not a follow-up test to further explore the relationship between variables but rather is a part of the multiple regression analysis. The parameter table presents an Estimate coefficient which is the standardized regression coefficient and indicates the expected change in the dependent variable associated with a unit change in the independent variable under consideration, while controlling for the effects of the other independent variables (Pedhazur, 1982). In Hypothesis 1 one unit change in grandparents' age is associated with a .007 unit loss in grandparents' needs score controlling for the effect of the remaining grandparent and grandchild characteristics. An important distinction between the Estimate and a correlational coefficient is that the Estimate represents the relationship controlling for the effect of the remaining eight grandparent and grandchild characteristics while the correlational coefficient does not. This distinction also explains why the Estimate is not the same as  $R^2$ . The  $R^2$  is tantamount to testing all the

independent variables simultaneously, therefore  $R^2$  does not relate to the independent variables separately (Pedhazur, 1982).

A decision rule was established for use in determining whether to reject a hypothesis. The decision rule states that a hypothesis will be rejected when the regression coefficient is significant at the  $p < .05$  level.

#### Relationships between independent and dependent variables

Table 17

#### Correlation Matrix of Independent and Dependent Variables

Independent	Dependent		
	Family Needs Scale	Family Support Scale	Family Adaptation and Cohesion Evaluation Scale II
Grandparent Age	0.017	0.128	-0.004
Grandparent Race	-0.347**	0.153	0.195
Grandparent Gender	0.055	-0.035	-0.177
Grandparent Marital Status	-0.063	0.179	0.251**
Grandparent Health Status	-0.165	0.110	0.186
Grandparent Socioeconomic Status	-0.313**	-0.068	0.109
Lineage Connection - Son's Child	-0.110	-0.055	0.199
Lineage Connection - Daughter's Child	0.092	-0.057	-0.098
Grandchild Age	0.021	-0.061	-0.074
Grandchild Gender	0.053	-0.090	-0.157

Note. \*\* Significant at the  $p < .05$  level.

Prior to running the regression analyses, for each hypothesis, a Pearson Product Moment correlation was calculated for each pair of independent and



dependent variables. The information from this analysis may assist in interpretation of the analyses of the hypotheses. The results are presented in Table 17.

The relationship between the custodial grandparents' race and their needs was negative and significant. Caucasian custodial grandparents had fewer unmet or inadequately met needs than did the minority custodial grandparents. Another significant relationship was that between the custodial grandparents' socioeconomic status and their needs. This relationship was also negative indicating that the higher the custodial grandparents' annual family income the lower the number of their unmet or inadequately met needs. The third significant relationship, between custodial grandparents' marital status and adaptation, was positive. Grandparents who were married, remarried, or living with a partner were better adapted. These relationships will be addressed further in discussion of Hypotheses 1, 2, and 3.

#### Analysis of Hypothesis 1

In Hypothesis 1, the relationship between the custodial grandparents' age, gender, race, marital status, health status, socioeconomic status, lineage connection to the grandchild, and the grandchild's age and gender and the custodial grandparents' perception of their needs was investigated. Demands were measured as the total needs score for the FNS. The relationship of all the independent variables to the needs experienced by custodial grandparents was investigated using multiple regression analysis. Results of the investigation into this hypothesis are presented in Tables 18 and 19. Table 18 presents the relationship of all nine grandparent and grandchild factors, as a whole, with the total needs of the custodial grandparents.

Table 18

Source Table of the Multiple Regression Analysis of Hypothesis 1

Source	$r^2$	df	F	p
Model	0.185	10	1.86	0.0629
Error		82		

Results of the multiple regression analysis indicate that the custodial grandparents' age, gender, race, marital status, health status, socioeconomic status, and lineage connection to the grandchild, and the grandchild's age and gender do not predict the custodial grandparents' perception of their needs; therefore, H1 is not rejected. The relationship of each grandparent or grandchild characteristic, while controlling for the remaining characteristics, is presented in Table 19.

Table 19

Variable Table of the Multiple Regression Analysis of Hypothesis 1

Source	Estimate	Standard Error of Estimate
Grandparent Age	-0.007	0.017
Grandparent Gender	0.094	0.369
Grandparent Race	-0.678**	0.279
Grandparent Marital Status	0.198	0.267
Grandparent Health Status	-0.293	0.262
Grandparent Socioeconomic Status	-0.171**	0.085
Lineage Connection - Son's Child	0.221	0.509
Lineage Connection - Daughter's Child	0.259	0.485
Grandchild Age	0.016	0.083
Grandchild Gender	-1.658	0.250

Note. \*\* Significant at the  $p < .05$  level.

Although H1 is not rejected, results of the correlation analysis (see Table 17) and the regression analysis (see Table 19) indicate that a predictive relationship does exist between the needs of custodial grandparents and their race and socioeconomic level. Caucasian custodial grandparents perceived that they had fewer unmet needs than did custodial grandparents who were African-American or Hispanic. Also, the greater the custodial grandparents' annual family income, the fewer needs they perceived as being unmet. Therefore, H1.3 and H1.6 are rejected. The remaining hypotheses, H1.1, 2, 4, 5, 7, 8, and 9, are not rejected.

### Analysis of Hypothesis 2

Hypothesis 2 examined the relationship between the custodial grandparents' age, gender, race, marital status, health status, socioeconomic status, lineage connection to the grandchild, and the grandchild's age and gender and the custodial grandparents' perceptions of their capabilities. Capabilities were measured as the total support score for the FSS. The relationship of all the independent variables to the capabilities of custodial grandparents was investigated using multiple regression analysis. The results of these analyses are presented in Tables 20 and 21.

Table 20

### Source Table of the Multiple Regression Analysis of Hypothesis 2

Source	$r^2$	df	F	p
Model	0.138	10	1.31	0.2382
Error		82		

The results of the multiple regression analysis indicate that the relationship between custodial grandparents' age, gender, race, marital status,

health status, socioeconomic status, and lineage connection to the grandchild, and the grandchild's age and gender and the custodial grandparents' capabilities is not predictive; therefore, the hypothesis is not rejected. However, the regression analysis as presented on the parameter table indicates that a predictive relationship does exist between the custodial grandparents' perception of their capabilities and their marital status.

Table 21

Variable Table of the Multiple Regression Analysis of Hypothesis 2

Source	Estimate	Standard Error of Estimate
Grandparent Age	0.027	0.015
Grandparent Gender	0.027	0.325
Grandparent Race	0.331	0.246
Grandparent Marital Status	0.503**	0.235
Grandparent Health Status	0.319	0.230
Grandparent Socioeconomic Status	-0.141	0.075
Lineage Connection - Son's Child	0.354	0.447
Lineage Connection - Daughter's Child	0.186	0.427
Grandchild Age	-0.030	0.073
Grandchild Gender	-0.128	0.220

Note. \*\* Significant at the  $p < .05$  level.

The relationship between the custodial grandparents' perception of their capabilities and their marital status indicates that custodial grandparents with a spouse or partner perceived their capabilities as more helpful than those who were divorced, widowed, or single. The significance of this relationship is not

supported by the correlational data (see Table 17) which does not control for other grandparent or grandchild characteristics. It may be that an interaction between marital status and another grandparent or grandchild characteristic masks the effect of marital status, unless controlled. Based on the decision rule established for rejection of hypotheses, H 2.4 was rejected. The remaining hypotheses, H2.1, 2, 3, 5, 6, 7, 8, and 9, were not rejected.

### Analysis of Hypothesis 3

Hypothesis 3 addresses the custodial grandparents' age, gender, race, marital status, health status, socioeconomic status, lineage connection to the grandchild, and the grandchild's age and gender relationship to the custodial grandparents' perception of their adaptation. Family adaptation and cohesion were measured through the total adaptation scaled score of the FACES II. The relationship of all the independent variables together to the adaptability of custodial grandparents was investigated using a multiple regression analysis. Results of the investigation into this hypothesis are presented in Tables 22 and 23.

Table 22

### Source Table of the Multiple Regression Analysis of Hypothesis 3

Source	$r^2$	df	F	p
Model	0.2014	10	2.068	0.0365
Error		82		

The data indicate a significant relationship between the predictor variables and the custodial grandparents' adaptation; therefore, this hypothesis is rejected. Data presented in the Pearson Product Moment correlation matrix (see Table 17) and the parameter table (see Table 23) also indicate a

significant relationship between the custodial grandparents' marital status and their adaptation.

When all other variables are held constant, custodial grandparents who were married, remarried, or living with a partner perceived their families to be better adapted than did divorced, widowed, or single custodial grandparents, therefore H 3.4 was rejected. The correlational data indicates that this relationship is weak. The significant relationship between custodial grandparents' adaptation and raising the son's child is not supported by the correlational data. However, based on the decision rule H3.7 was also rejected. The remaining hypotheses, H3.1, 2, 3, 5, 6, 8, and 9, were not rejected.

Table 23

Variable Table of the Multiple Regression Analysis of Hypothesis 3

Source	Estimate	Standard Error of Estimate
Grandparent Age	0.008	0.006
Grandparent Gender	-0.157	0.135
Grandparent Race	0.068	0.102
Grandparent Marital Status	0.219**	0.098
Grandparent Health Status	0.178	0.096
Grandparent Socioeconomic Status	-0.027	0.031
Lineage Connection - Son's Child	0.388**	0.186
Lineage Connection - Daughter's Child	0.193	0.178
Grandchild Age	-0.006	0.030
Grandchild Gender	-0.095	0.092

Note. \*\* Significant at the  $p < .05$  level

### Analysis of Hypothesis 4

The relationship between custodial grandparents' perception of the demands they experience and their perceptions of their capabilities was investigated by Hypothesis 4. The capabilities of custodial grandparents were measured by the total support score of the FSS. The needs custodial grandparents experience were measured by the total needs score of the FNS. This hypothesis was investigated through a simple bivariate regression test. The results of this investigation are presented in Table 24 and indicate that there is no predictive relationship between the custodial grandparents' needs and their capabilities. Therefore, Hypothesis 4 was not rejected.

Table 24

#### Source Table of the Simple Bivariate Regression Analysis of Hypothesis 4

Source	r <sup>2</sup>	df	F	p
Model	0.016	1	1.519	0.2210
Error		91		

Table 25

#### Correlational Data for Family Needs Scale, Family Support Scale, and Family Adaptation and Cohesion Evaluation Scale II

Instrument	Family Needs Scale	Family Support Scale	Family Adaptation and Cohesion Evaluation Scale
Family Needs Scale	1.000	0.128	-0.269**
Family Support Scale		1.000	0.264**
Family Adaptation and Cohesion Evaluation Scale			1.000

Note. \*\* Significant at the  $p < .05$  level

Presented in Table 25 are the correlational data for the relationship between the total scaled scores of the FNS, FSS, and FACES II. These data also indicate that no significant relationship exists between the FNS and the FSS.

#### Analysis of Hypothesis 5

The relationship between the demands custodial grandparents experience and custodial grandparents' adaptation was investigated in Hypothesis 5. Custodial grandparents' needs were measured by the total needs score of the FNS. Custodial grandparents' adaptation was measured by the total adaptation scaled score of the FACES II. This hypothesis was investigated through a simple bivariate regression analysis. The results of this investigation are presented in Table 26.

Table 26

#### Source Table of the Simple Bivariate Regression Analysis of Hypothesis 5

Source	$r^2$	df	F	p
Model	0.072	1	7.100	0.0091
Error		91		

The results of the investigation into this hypothesis indicate that the more unmet needs custodial grandparents experience the weaker will be their families' total adaptation. The Pearson Product Moment correlational data in Table 23 supports this finding. Based on the significance of this relationship, Hypothesis 5 was rejected.

#### Analysis of Hypothesis 6

Hypothesis 6 addressed the relationship between the custodial grandparents' capabilities and the custodial grandparents' adaptation. This



hypothesis was also investigated through a simple bivariate regression model. The capabilities of custodial grandparents were measured by the total support score of the FSS. Custodial grandparents' adaptation was measured by the total adaptation scaled score of the FACES II.

Table 27

Source Table of the Simple Bivariate Regression Analysis of Hypothesis 6

Source	$r^2$	df	F	p
Model	0.0696	1	6.812	0.0106
Error		91		

Table 27 presents the results of this investigation, which indicate that the relationship between the custodial grandparents' capabilities and adaptation was significant but weak. The correlational data in Table 23 support the finding of a significant, positive relationship between custodial grandparents' capabilities and adaptation. Indications are that the more helpful custodial grandparents perceived their support systems to be the better they perceived their family adaptation and cohesion. Due to the significance of the relationship, Hypothesis 6 was also rejected.

Summary of the Findings

With regard to the first major question of the study, evidence was presented that suggests that the grandparent and grandchild factors, as a whole, were not predictive of the demands experienced by custodial grandparents. However, evidence was presented that indicated that a predictive relationship does exist between custodial grandparents' race and socioeconomic status and their perception of their needs.

Evidence was presented regarding the second major question, which suggests that the grandparent and grandchild factors, taken together, are not predictive of the custodial grandparents' perception of their capabilities. A significant relationship was evidenced, however, between the custodial grandparents' marital status, controlling for all other independent variables, and their capabilities.

Investigation addressing the third major question of the study presented evidence suggesting a predictive relationship between the grandparent and grandchild factors, in total, and the custodial grandparents' perception of their family adaptation. Investigation of the data from regression and correlational analysis for this hypothesis indicated a significant relationship between marital status and custodial grandparents' adaptation. The regression analysis also revealed a positive, significant relationship between the custodial grandparents' adaptation and the grandchildren's lineage connection through the son.

The investigation into the fourth and final major question of the study indicates that a predictive relationship does not exist between the custodial grandparents' perceptions of their needs and capabilities. However, a custodial grandparents' needs are predictive of their adaptation. The more adequately met their needs the better the custodial grandparents' adaptation. Custodial grandparents' capabilities are also predictive of their adaptation. The more helpful the custodial grandparents' resources the better their adaptation.

In the next chapter, I will compare and contrast the results of this study with studies of parents and grandparents reviewed in Chapter Two. I will also discuss the data in terms of their implications for Family Systems Theory operationalized by the FAAR Model. Chapter Five will end with implications of the results for the Family Systems Theory as operationalized by the FAAR Model and Early Intervention, as well as for future family research.

## CHAPTER FIVE DISCUSSION OF THE RESULTS AND IMPLICATIONS FOR FURTHER RESEARCH

### Summary of the Study

In this study, I investigated the perceptions of custodial grandparents regarding the demands they experience, their capabilities, their family adaptation, and the relationships among these factors. I also studied relationships among certain grandparent and grandchild factors and custodial grandparents' needs, capabilities, and adaptability. This investigation was conducted through dissemination and collection of a survey booklet consisting of a family demographic survey and three questionnaires: (a) the *Family Needs Scale* (FNS) (Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1987; 1988), (b) the *Family Support Scale* (FSS) (Dunst, Jenkins, & Trivette, 1984; Dunst, Trivette, & Jenkins, 1988), and (c) the *Family Adaptation and Cohesion Evaluation Scales* (FACES) II (Olson, Portner, & Bell, 1982; Olson, Bell, & Portner, 1991). Demographic information regarding the grandparents' age, age of entry into grandparenthood, gender, race, marital status, health status, socio-economic status, and lineage connection to the custodial grandchild, and the age and gender of the custodial grandchild was requested on the survey.

Participants for this study consisted of custodial grandparents of young children, ages birth through 5 years, with disabilities or at risk for disabilities residing in the state of Florida who were receiving services from the Department of Health and Rehabilitative Services (HRS) or were members of local grandparent organizations. Confidentiality prevented disclosure of potential participants' personal information; therefore, the HRS agency or grandparent

organization assigned a contact person to oversee dissemination of surveys and reminder postcards. A packet for each potential participant, consisting of a cover letter, grandparent survey instruments, and self-addressed stamped return envelope, was provided to the contact person. Four weeks after the initial mailing date, reminder postcards were mailed to recipients who had not returned their survey packets. One week after the first reminder postcards were mailed, second reminder postcards were sent.

Due to the low return rate (13%) on the initial 200 surveys, additional surveys were disseminated to previously untapped HRS districts. However, the first reminder postcards were mailed after 10 days. Rather than sending second reminder postcards, a second copy of the survey and a new cover letter were mailed 15 days after the initial mailing.

A total of 377 survey packets was disseminated, of which 135 (37%) were returned. However, after eliminating surveys that could not be scored due to incomplete responses or ineligibility as a result of age of child or relationship with the child, a sample of 93 (25%) grandparents was obtained. Data were then analyzed.

In this chapter I present a discussion of the results of this investigation and their implications for theory and practice. Limitations of this study and future research needs are also discussed.

### Discussion of the Results

In this section I will discuss the results of this investigation of custodial grandparents raising young grandchildren with disabilities or at risk for disabilities. First, I discuss the return rate, next the sample, and finally the scaled scores for each of the instruments.

### The Return Rate

The return rate of 25% was lower than the criteria established at the beginning of this study and was judged to be problematic in regards to generalizing the results to a larger population. Possible explanations for the low return rate include the limited accessibility of the population due to confidentiality restraints and contact through a third party. The limited systematic organization of custodial grandparents as a cohort may have also affected the return rate. Due to the relatively recent emergence of custodial grandparents as a population for research, the lack of previous quantitative research on this population, and the inferential nature of this study, the low return rate and small sample size are not prohibitive. The sample did not possess any identifiable characteristics that would make it inappropriate for this study. All inappropriate respondents were eliminated from the sample prior to analysis of the data. Therefore, it is possible to test Family Systems Theory as operationalized by the Family Adjustment and Adaptation (FAAR) model with these data.

Due to the limited availability of research on custodial grandparents raising young children with disabilities or at risk for disabilities, I will also discuss these results in relation to other studies of parents and grandparents. However, I do realize the caution with which such generalizations must be made and am doing so only to further the discussion of the needs, capabilities, and family adaptation of custodial grandparents as a diverse population. I caution the reader against generalizing these results or the following discussion to all custodial grandparents.

### The Sample

Cowan, Hansen, Swanson, Field, and Skolnick (1993) noted that the heterogeneity of families makes it clear that no single homogeneous data set can truly represent "the family." They stated that family researchers do not really

know whether the same laws of system structure and function apply to diverse family structures. It is clear that family research should include diverse family structures and apply the laws of system structure and function to each of them to see if these laws do, indeed, apply. Therefore, the relative homogeneity of the families in earlier research becomes problematic when applying each study's results to the custodial grandparent family. We are, essentially, comparing custodial grandparents of diverse socio-economic, age, racial, and marital status with white middle income, married parents; low socio-economic level, urban African-American custodial grandparents; or white middle socio-economic level noncustodial grandparents. However, as the purpose of this study was to test family systems theory and not describe custodial grandparent families, this limitation is not prohibitive. In this section I briefly describe and compare the average custodial grandparents participating in this study and the samples of parents and grandparents participating in earlier investigations. The reasons for doing so are twofold. To point out the range of responses from the families studied and to expand the discussion of families to include more diverse populations and structures.

The grandparents participating in this investigation ranged in age from 35 to 72 years with the majority being in their late 40s and early 50s. Both males and females, and maternal and paternal grandparents were represented. Although the majority of grandparents participating in this study were Caucasian, some African-Americans and Hispanics participated. The majority of the grandparents were either married or living with a partner. Most reported their annual family income to be less than \$30,000.

Although some fathers and minority and single parents participated in earlier investigations of parents' needs, capabilities, and adaptation, the parents were primarily female, Caucasian, married, and within the middle socio-

economic level. Unlike the average custodial grandparents in this study, most custodial grandparents involved in previous investigations were African-American and from lower socio-economic levels. However, these studies did include both males and females, and maternal and paternal grandparents.

In previous studies grandparents' ages ranged from 43 to 90 years; they were older than the grandparents in this study and more compatible with society's perception of grandparenthood. As with the average custodial grandparents in this study, the predominant reason custodial grandparents from previous studies cared for their grandchildren was the parents' substance abuse.

In this investigation, custodial grandparents' responses to open-ended questions indicated that the majority of the grandchildren's risk conditions included exposure to parental substance abuse, parental neglect and abuse, and financial hardship. The grandchildren of the average custodial grandparents in this study were either diagnosed with a disability or at risk for a disability. The diagnoses varied as did the severity of the disabilities. The ages of the grandchildren ranged from less than a year up to 6 years.

Unlike the children in this investigation, the majority of the children of the parents involved in previous studies had a diagnosed disability. In this and previous studies, the diagnoses of the children with disabilities varied as did the severity of their disabilities. The children in previous studies ranged in age from birth to adulthood; by contrast the children in this study were no older than 6.

The grandchildren of the custodial grandparents in previous studies were closer in age of the children in this study; most were under 13 years of age. Few studies of custodial grandparents have focused on grandparents of children with disabilities or at risk for disabilities. However, some disabilities

have been evident. If the grandchildren had disabilities, the disabilities were typically a result of prenatal exposure to drugs.

Overall the description of the participants in this study helps to broaden the focus of family research in three ways. First, the nontraditional structure of the custodial grandparents' families, in comparison to parent-child families, may expand the availability of empirical research on custodial grandparents raising young grandchildren with disabilities or at risk for disabilities. Second, the nontraditional structure of these families also challenges Family Systems Theory as operationalized by the FAAR Model with a data set that represents an alternate definition of family. Third, this data set adds to the emerging research on custodial grandparent families by including younger grandparents; broadening the spectrum of marital, racial, and socio-economic status of custodial grandparents being investigated; and including grandchildren with a range of disabilities.

### The Scaled Scores

In the following sections, I will describe the scaled scores for the Family Needs Scale (FNS), Family Support Scale (FSS), and Family Adaptation and Cohesion Evaluation Scale (FACES) II. I will also link the scaled scores of the needs, capabilities, and adaptation of custodial grandparents to those of the parents and custodial grandparents in previous investigations. The purpose behind this investigation is to address the implications of the custodial grandparent family for early interventionists providing family centered services to custodial grandparents who participated in this study. Early interventionists are called upon to develop family centered programs and to collaborate with families to write Individual Family Service Plans (IFSP) and Individual Education Programs (IEP). Historically, early interventionists have worked with parents of young children. The marital status of the parents has changed with



time to include more single parents and step-parents as well as traditional two parent families. Early interventionists have made this adjustment in their perspective. As young children of teenage mothers have entered early intervention programs, early interventionists have also adjusted their perspective to work with these young mothers and in some cases their mothers. However, the underlying expectation of early interventionists is that they will be working with parents.

What happens when these expectations conflict with the reality of custodial grandparents? In linking the results of previous literature to the results of this study, it became apparent that although there were similarities between there were also differences. Whether these differences are a result of different methodology, instrumentation, or sample representativeness is unclear. The explanation for the differences may be that this group of custodial grandparents of young children with disabilities or at risk for disabilities is not a representative sample or that custodial grandparents of young children with disabilities or at risk for disabilities are not the same as custodial parents of children with disabilities, custodial grandparents of nondisabled grandchildren, or noncustodial grandparents. It is important to note the range of responses within this particular sample of custodial grandparents. This range of responses indicates that early interventionists must not mistakenly assume all custodial caregivers will have the same demands, capabilities, or adaptation.

#### Family needs scale

In this investigation demands were measured with the Family Needs Scale (FNS). The Family Needs Scale (Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1987; 1988) measures the need for different resources and support in the family's household. The domains of the FNS include needs from all levels of the family system. In this section the demands experienced by custodial

grandparents who participated in this study are linked to previous investigations of demands experienced by parents of children with disabilities and other custodial grandparents.

Overall, there appear to be needs that are common to parents who are raising children with disabilities or custodial grandparents of nondisabled children and the custodial grandparents in this study. Custodial grandparents who participated in this study and parents who participated in previous studies identified a need for information (Bailey & Simeonsson, 1988; Irwin, 1992), respite care (Bailey & Simeonsson, 1988; Gowen, Christy, & Sparling, 1989; McLinden, 1990; Petr & Barney, 1991), financial assistance (Petr & Barney, 1991), long term planning (Bailey, Blasco, & Simeonsson, 1992), and contact with other families of children with disabilities (Bailey & Simeonsson, 1988). There were also similar needs identified by custodial grandparents from previous studies and the custodial grandparents in this study. Both sets of custodial grandparents identified respite care (Burton, 1992a), multiple roles (Burton, 1992a), financial assistance (Dressel & Barnhill, 1992) and long term planning (Burton, 1992a) as demands that they experience. Although the demands experienced by the three groups may appear similar the content or specifics of these demands may differ.

Information needed by custodial grandparents may differ from the information needed by parents. Custodial grandparents may need information not only regarding their grandchildren's diagnosis and service options but also about the grandparents' legal rights, legal aide, writing a will, setting in place arrangements for when the grandparents are no longer able to care for the grandchildren, money management, strategies to cope with the grandchildren's parents' behaviors, or rehabilitation programs for the grandchildren's parents. Grandparents noted that they would like to talk to other grandparents to see

how they cope with their worries about childrearing practices and the future. Many custodial grandparents remarked that they just didn't understand how their children, their custodial grandchildren's parents, could abuse the grandchildren, abuse drugs, or be in trouble with the law. This may reflect Burton's (1992a) and Droddy's (1993c) findings that custodial grandparents needed to learn strategies for coping with the circumstances that led to their assuming custodial caregiving responsibilities.

Parents' informational needs may also involve their children's diagnosis and service options, what to expect for their children's future, employment assistance, their legal rights and those of their children, or financial aide. Although on the surface the needs of parents and custodial grandparents appear similar, there may be very different skills and information required to meet these needs. This complexity of similarities and differences must be understood and addressed by early interventionists in developing family centered intervention programs, IFSPs, and IEPs. In this study, the average custodial grandparents perceived that their needs were sometimes, but not often, adequately met.

The variability in responses indicated that while some custodial grandparents perceived their needs as often being adequately met other custodial grandparents perceived their needs as never adequately met. The strain of inadequately met needs can become stressors and, according to Patterson (1988, 1993), is predictive of poor family adjustment or adaptation. Patterson noted that if families perceive that the nature or number of their needs exceeds their capabilities, they are no longer able to adjust or adapt and are in crisis. If so not only may the average custodial grandparents in this study have inadequately met needs, but their unmet needs may be stressors hampering the custodial grandparents' adaptation. I show in the discussion of the responses

on the FACES II and the investigation into Hypothesis 5, this statement appears correct for the custodial grandparents participating in this study. Patterson (1988) also noted that families try to maintain their state of adjustment or adaptation by using their capabilities. It is as important for early interventionists to understand the custodial grandparents' capabilities as it is for them to understand the custodial grandparents' needs.

#### Family support scale

According to the FAAR Model, capabilities consist of resources and coping behaviors. Resources are the people and skills the family has to help them balance their needs. Resources may be available from the individual, the family system or subsystems, or the suprasystem. This investigation measured the custodial grandparents' resources with the *Family Support Scale* (Dunst, Jenkins, & Trivette, 1984; Dunst, Trivette, & Jenkins, 1988). In this section, I will discuss the scaled scores of the FSS and link them with the perceived capabilities of the parents and custodial grandparents from previous investigations.

Overall, there were distinct differences between the capabilities of the parents of children with disabilities who participated in previous studies and the average custodial grandparents who participated in this study. Parents in previous studies identified other parents of children with disabilities (Kazak & Marvin, 1984; Naseef, 1989; Petr & Barney, 1991), their church (Naseef, 1989; Petr & Barney, 1991), their spouse (Naseef, 1989; Todis & Singer, 1991), their families, (Barney, 1991), and professional helpers (Kazak & Marvin, 1984) as sources of support. Custodial grandparents who participated in this study indicated that these same resources were of limited support to them.

Unlike the parents of children with disabilities, many custodial grandparents remarked that they did not have access to or knowledge of peers

(i.e., other grandparents who were raising grandchildren). Although some custodial grandparents did comment on the strength they received from their faith, belief in God and Jesus, and prayer, the average custodial grandparents identified their church as only somewhat helpful. Spousal or partner support was very helpful for some of the custodial grandparents while others commented on the stress raising the grandchildren was placing on their marital relationships. Other custodial grandparents commented that their spouse or partner was unable to provide support due to ill health or un- and under-employment; indeed, these spouses required support themselves.

Most custodial grandparents, in response to open-ended questions, reported that their children and other family members provided little, if any, support. In most cases, the reason the custodial grandparents were raising their grandchildren was that the social services and the legal system had removed the grandchildren from their parents' care. Reasons for this removal were primarily alcohol and drug abuse. Social services and the courts were not perceived as very helpful by the average custodial grandparents. Many grandparents reported a lack of financial, legal, physical, or emotional support from professional services. The prevalent feelings among these custodial grandparents were uncertainty and anger regarding the professional services they did receive.

Although there were many differences between the custodial grandparents in this study and parents in previous studies, there were some similarities between the custodial grandparents in this study and custodial grandparents in other studies. Burton (1992) reported that custodial grandparents could benefit from receiving support from their church, community, and government agencies.

The custodial grandparents of this study and other studies appear to have less helpful resources than do parents from previous investigations. Three important differences are the helpfulness of other families with children with disabilities (Jendrek, 1992b; Naseef, 1989; Petr & Barney, 1991), their own families (Barney, 1991; Naseef, 1989; Petr & Barney, 1991; Todis & Singer, 1991), and of professional services (Burton, 1992; Kazak & Marvin, 1984).

A possible explanation for the limited familial support to the grandparents participating in this study is the traditional use of maternal grandparents as a safety net in times of crisis or need. Grandparents who are raising their grandchildren may not have a safety net of their own. The custodial grandparents' own parents may be unable or unavailable to assist them. Children and other family members may be too involved in raising their own children or grandchildren, in their education or employment, or in other activities to provide support to custodial grandparents.

The average custodial grandparents in this study identified fewer capabilities than did parents in previous investigations and the capabilities the custodial grandparents did identify were of limited helpfulness. Based on Patterson's (1988, 1993) explanation of capabilities, the custodial grandparents in this study may be at risk for depleting their capabilities. Depleted capabilities will leave the custodial grandparents little in reserve with which to adapt to their demands. The results of the test of Hypothesis 6 confirm the relationship between the average custodial grandparents' capabilities and adaptation. The custodial grandparents' responses to the FACES II indicate that Patterson's prediction may be true.

#### Family adaptation and cohesion evaluation scales II

In this section, I review the scaled scores for the custodial grandparents' family adaptation and compare them to the adaptation of parents of children

with disabilities and custodial grandparents participating in previous studies.

Family adaptation is measured using the *Family Adaptation and Cohesion Evaluation Scales II* (Olson, Portner, & Bell, 1982; Olson, Bell, & Portner, 1991).

Family adaptation is obtained by combining the family cohesion and family adaptation domain scores. As with the FNS and FSS, the range of responses on the FACES II is as informative as is the response of the average custodial grandparents who participated in this investigation.

Initially, there appear to be similar adaptive characteristics between the average custodial grandparents and parents from previous studies. However, overall, the custodial grandparents in this study appear to be functioning in the range of an extreme family type. This is different from parents of children with disabilities whose overall adaptation is the same as parents of children without disabilities.

It would appear that although similar characteristics are indicated by both sets of family types, the degree to which the families experience the characteristics is different. It should also be noted that gender effects were evident in the parental responses so that some of the similar characteristics were not experienced by both parents.

Single mothers were less satisfied with their families, recreation, and needs on their time than were married mothers (Kazak & Marvin, 1984; Schilling, Kickham, Snow, & Schnike, 1986). Custodial grandparents were also dissatisfied with their families, recreation, and needs on their time. Many custodial grandparents in this study reported they had not expected to be raising their grandchildren and were only doing so because they didn't want the grandchildren to go to strangers. Custodial grandparents also stated that they did not have enough time to spend on themselves or with other family members.

Parents of children with disabilities felt more role restrictions in their parenting than did parents of children without disabilities (Beckman, 1991). Custodial grandparents indicated feelings similar to those of parents when they reported that they had not expected to be raising their grandchildren and felt more like a parent than a grandparent. Some custodial grandparents commented that they would be glad when they were no longer raising the grandchildren and they could just be grandparents.

Parents of children with disabilities also felt more familial stress than did parents of children without disabilities (Dyson, 1987; Dyson & Fewell, 1988). Custodial grandparents in this study commented on the lack of assistance from other family members, especially the custodial grandchildren's parents. Most grandparents stated that their relationship with the grandchildren's parents was stressed, often to the point of no contact at all. The custodial grandparents indicated that they felt confusion over the parents' behavior in general and towards the grandchildren specifically. The custodial responsibilities were also placing stress on many custodial grandparents' finances and marital relationships.

Parents of children with disabilities also emphasized rules and control more than parents of typically developing children (Dyson, 1987; 1991). Some custodial grandparents in this study also commented that in raising their grandchildren they were trying to avoid the mistakes they had made raising their children. One grandparent noted that the problems her daughter was experiencing were a result of schools and society that were too lenient. Many custodial grandparents in this study noted that their grandchildren were too young to be involved in family decision making, establishing rules, or deciding punishment.



Although it appears that the average custodial grandparents in this study and parents from previous studies have similar adaptive characteristics there are differences. Parents of children with disabilities from other studies have indicated some adaptive problems on various factors contributing to the total score but their total adaptation scores did not indicate adaptive problems. Custodial grandparents in this study have indicated problems on the cohesion and adaptation factors as well as their total adaptation score. It appears that the degree that the adaptive characteristics are felt by the parental and custodial grandparent families are different. The average custodial grandparents in this study appear to be functioning in the extreme family type range.

Possible explanations for this difference may be the number of unmet needs of the custodial grandparents, or the limited capabilities of the average custodial grandparents. As we will see in discussion of Hypotheses 3, 5, and 6, the grandparents' and grandchildren's characteristics, demands, and capabilities are related to their adaptation. However, prior to discussing the hypotheses, the relationship among variables will be discussed briefly.

#### Discussion of the Analysis of the Data

In this section I discuss the relationships among the variables and the testing of the hypotheses.

#### Analysis of the relationships among variables

The relationships among the variables were investigated to help determine which, if any, independent variables could be eliminated from the model. As the correlational data have been discussed in previous sections of this document, I will forego a repetition of this information. The relationships between variables were also of interest in regards to their relationship to the hypotheses of this study. Variable relationships will be discussed in the following section as they relate directly to the hypotheses.

### Analysis of the hypotheses

In this section I will discuss each hypothesis tested in this investigation. The hypotheses will be discussed as they relate to each of the four research questions. First, research question 1 and Hypothesis 1 will be discussed. Then research question 2 and Hypothesis 2, research question 3 and Hypothesis 3, and finally research question 4 and Hypotheses 4, 5, and 6 will be discussed.

Research Question One. The first research question of this study was an inquiry into the relationship between the needs experienced by grandparents and specific grandparent and grandchild variables. Hypothesis 1 addressed this question.

Overall, results of the investigation indicate that the relationship between the custodial grandparents' age, gender, race, marital status, health status, socio-economic status, and lineage connection to the grandchild, and the grandchild's age and gender and the demands custodial grandparents experience is not significant. This indicates that knowledge of all the variables included in this hypothesis does not assist in predicting custodial grandparents' needs.

However, it would appear that, for the average custodial grandparents in this investigation, their annual family income and race do provide some insight into custodial grandparents' needs. I found that the lower the annual family income of custodial grandparents in this study, the more unmet needs they perceived. I also found that minority custodial grandparents participating in this investigation perceived more unmet needs than did Caucasian custodial grandparents. The findings of a possible relationship between grandparents' needs and their socio-economic status or race, holding all other variables constant, is interesting but not unexpected, especially in light of the significant and moderately strong association of race and socio-economic status (see

Table 16). This correlational relationship indicates that African-American and Hispanic custodial grandparents have a lower annual family income than do Caucasian custodial grandparents. It would appear that custodial grandparents representing minority races have fewer financial resource(s) with which to address their needs and therefore perceive that they have more unmet needs.

The presence of significant relationships between custodial grandparents' needs and their annual family income and race is contrary to Droddy's (1993c) research with custodial grandparents. The results of Droddy's study indicated that income or race had no effect on the needs experienced by custodial grandparents. However, the absence of significant relationships between the other grandparents and grandchildren characteristics supports Droddy's findings of no health or age effect on the needs of custodial grandparents.

The absence of significant relationships between each of the independent variables and the custodial grandparents' perception of their needs is different from the findings of previous research on parents and custodial grandparents. McLinden (1990), Bailey, Blasco, and Simeonsson (1992), and Kazak and Marvin (1984) noted a gender effect with mothers of children with disabilities experiencing more needs than fathers. Brown (1990) reported a marital effect. Brown noted that single mothers reported more stress than did married mothers. Frey, Greenberg, and Fewell (1989) noted a child gender effect. They reported that the parents of sons with disabilities experienced more needs than did other parents.

A possible explanation for the absence of individual grandparent and grandchild variable effect is that custodial grandparents of young children with disabilities or at risk for disabilities are different from parents of children with disabilities. Comparison of the demographics of the grandparents who

participated in this study and parents from previous studies shows that the average grandparents in this study were older and from lower socioeconomic levels. The majority of parents participating in previous studies were younger and from the middle socioeconomic level. The parents participating in previous study represented intact families, whereas the custodial grandparents in this study represented a nontraditional family structure.

Another explanation for the absence of grandparent and grandchildren characteristic effects may be the incongruence between the custodial grandparents' current role and the role they expected to play in their grandchildren's lives. Some custodial grandparents commented to open-ended questions that primary caregiving was not the role they had expected or wished to play with their grandchildren. Custodial grandparents also reported that they would be glad when they were no longer raising the grandchildren and could be just a grandparent. The incongruence between the custodial grandparents' definition and expectations of grandparenting and their current role may suppress the effects of the individual grandparent or grandchildren factors.

The results of the analyses for Hypothesis 1 indicate that in terms of what affects their needs, custodial grandparents of young children with disabilities are different from parents of children with disabilities and from custodial grandparents of grandchildren without disabilities.

Research Question Two. The second research question addressed the relationship between the capabilities of custodial grandparents and specific grandparent and grandchild variables. Hypothesis 2 investigated this second question.

Overall, the investigation into this hypothesis indicates that the relationship between the custodial grandparents' and the grandchildren's

characteristics and the average custodial grandparents' capabilities is not significant. In other words, knowing the information provided by all the independent variables does not help predict the helpfulness of the average custodial grandparents' capabilities. An individual effect was found between marital status and the custodial grandparents' capabilities when controlling for the other individual factors. Custodial grandparents who were either married or living with a partner perceived their capabilities as more helpful.

The relationship between marital status and capabilities is supported by previous research into parents' capabilities. Crnic, Greenberg, Ragozin, Robinson, and Basham (1983) found a marital effect. Married parents in their study identified more supports than did single parents.

The absence of a relationship between the average custodial grandparents' perception of their capabilities and the remaining grandparent and grandchild characteristics is surprising and inconsistent with findings of some previous research into parents' capabilities. Paez (1992) noted age, income, and race effects. Paez reported that older parents and parents of higher socio-economic levels reported greater capabilities. She also noted that Hispanic families had less intrafamilial capabilities. Bengston (1985) found a race effect on parental supports. Bengston noted that Hispanic parents had a larger social support network.

An explanation for the significant relationship between custodial grandparents' marital status and their capabilities in the partial regression analysis but lack of such a relationship in the correlational analysis is the suppressing effect of a negative indirect effect by another variable. The partial regression coefficient for marital status is the effect of marital status controlling for the effect of all other variables in the model, including the suppressing effect.

Another explanation for the absence of effect between custodial grandparents' and grandchildren's characteristics and capabilities is that custodial grandparents and parents differ demographically and functionally. Many of the custodial grandparents reported performing multiple roles -- parent, grandparent, custodial grandparent, spouse, worker, sibling, and caregiver for elderly parents. Many grandparents noted that their spouses were not in good health and were un- or under-employed. It fell upon the grandparent to provide physical, as well as financial, care to the custodial grandchild and spouse.

The custodial grandparents' own parents, the great grandparent, may be unavailable or unable to assist them in this time of need due to the great grandparents' age, health, geographic location, death, or involvement in raising their own grandchildren or great-grandchildren. Indeed, a few custodial grandparents remarked that their own parents were raising other relatives' young children and could not help them with their custodial grandchildren.

Many grandparents explained that the reason they were raising their grandchildren was the substance abuse, physical abuse, or legal problems of the grandchildren's parents. The custodial grandparents expressed anger, confusion, and pain over their children's behavior. Custodial grandparents also reported that their relationships with the biological parents were poor.

There was often ambiguity concerning what was the custodial grandparents' role or status. Custodial grandparents often felt more like parents than grandparents yet the grandchildren could be removed from their care at anytime. Many custodial grandparents expressed anger that the courts and social services placed the parents' rights over theirs and their grandchildren's.

The results of the analyses for Hypothesis 2 indicate that custodial grandparents of young children with disabilities are demographically and functionally different from parents of children with disabilities and noncustodial

grandparents. This difference is apparent in the absence of effect between custodial grandparents' and grandchildren's characteristics and capabilities.

Research Question Three. The third research question of this study was an inquiry into the relationship between the adaptation of custodial grandparents and specific grandparent and grandchild variables. Hypothesis 3 addressed this third question.

Overall, the investigation into this hypothesis indicates that the relationship between the custodial grandparent and grandchild factors and the average custodial grandparents' family adaptation is significant and moderately strong. This result indicates that knowing the information provided by all the independent variables helps to predict the custodial grandparents' perception of their family adaptation and cohesion. Two significant relationships also existed between individual factors and custodial grandparents' adaptation. The custodial grandparents' marital status was predictive of the custodial grandparents' total adaptation. The average custodial grandparents in this study who were married or remarried, or who had a partner, had better total family adaptation. The custodial grandparents' lineage connection to the custodial grandchildren was also predictive of the total family adaptation. Custodial grandparents raising their sons' children had better family adaptation.

The correlational analysis of the relationship between marital status and adaptation was also significant. However there was not a significant relationship between lineage connection through the son and adaptation. The incongruence between the regression and correlational analyses indicates a negative indirect effect by another variable is present which suppresses the lineage connection effect unless controlled for by the partial regression analysis.

A marital effect on parental adaptation was reported by Brown (1990), Crnic, Greenberg, Ragozin, Robinson, and Bosham (1983), and Schilling, Kirkham, Snow, and Schnike (1986). Single parents reported more difficulty adapting to children with disabilities than did married parents. In a study of noncustodial grandparents' satisfaction with their grandparent-grandchildren relationships, Thomas (1989b) also reported a marital effect. Grandparents who had a spouse were more satisfied with their relationships with their grandchildren than were grandparents who were not married.

Although previous studies on the typical grandparent and grandchild relationship also reveal a lineage connection effect, the effect is different than found in this investigation. Fischer (1983), Cherlin and Furstenberg (1986), and Hettinger (1989) reported that maternal grandparents have a more accessible relationship with their grandchildren and are more satisfied with these relationships. It should be noted that the largest percentage of custodial grandparents were maternal grandparents (raising their daughters' child). This reflects the increased accessibility indicated in Fischer, Cherlin and Furstenberg, and Hettinger. However, the custodial grandparents in this study who were raising their sons' children indicated that their sons provided more financial and physical support than did their daughters whose children they were raising.

Other parental effects in previous studies that were absent in this study include a grandparent gender effect and a child gender effect. Several researchers (Beckman, 1991; Bristol, Gallagher, & Schopler, 1988; Cook, 1988; Dyson & Fewell, 1988; Kazak, 1987; Kazak & Marvin, 1984; McLinden, 1990) noted that mothers had more problems adapting to children with disabilities than did fathers. Frey, Fewell, and Vadasy (1989) and Frey, Greenberg, and Fewell (1989) also reported that parents of girls with disabilities experienced



less parenting stress and had better overall adaptation than parents of boys with disabilities. Paez (1992) reported that minority families had lower adaptation to children with disabilities than Caucasian families. The previous research on custodial grandparents also indicates some custodial grandparent and grandchildren effects on adaptation. Shore (1991) and Shore and Hayslip (1993a) reported that grandparents raising grandsons had more difficulty adapting than grandparents raising granddaughters. Burton (1992a) noted a grandparent age effect, in which grandparents younger than 45 years experienced more difficulty adapting to raising their grandchildren. Drodgy (1993c) on the other hand, found no link between custodial grandparents' health, income, age, education, employment, or race and their adaptation to raising grandchildren.

Earlier research on grandparent adaptability investigated the noncustodial grandparents' satisfaction in their relationships with their oldest, geographically closest grandchildren. This research indicated a relationship between grandparent and grandchild factors and grandparents' adaptability, at least to the traditional grandparent-grandchild relationship. Grandparent age (Hettinger, 1989; Huish, 1991; Johnson, 1983; Mathews & Sprey, 1984; Thomas & Sanders, 1985), gender (Mathews & Sprey, 1984; Thomas, 1984; Thomas, 1989a; Thomas & Datan, 1983; Thomas & Sanders, 1985), health, (Thomas, 1989b), race (Bengston, 1985; Huish, 1991; Strom, Collinsworth, Strom, & Griswold, 1993), and grandchildren age effects (Huish, 1991) were found on noncustodial grandparents' satisfaction in their relationship with their grandchildren.

A possible explanation for the difference in number of effects for individual characteristics of parents and noncustodial grandparents than with the custodial grandparents in this study may be indirect effects which are not reflected in the partial regression analysis. Custodial grandparents' marital

status and lineage connection are more directly related to the custodial grandparents' adaptation than the remaining individual characteristics. The differences in custodial grandparents' demands and capabilities, as discussed in the previous section, may also contribute to the absence of individual effects on custodial grandparents' adaptation.

Another explanation for the relative absence of effects by individual characteristics is that most of the custodial grandparents in this study felt they had no choice in raising their grandchildren. A common response to open-ended questions was that grandparents did not want their grandchildren going to strangers or foster care, so they had to raise the grandchildren. This desire not to see the grandchildren in foster care may neutralize the effects of individual grandparent or grandchildren characteristics.

The results of the investigation into Hypothesis 3 indicate that the effects of individual grandparent or grandchildren characteristics are not the same for custodial grandparents as for parents of children with disabilities, custodial grandparents of children without disabilities, or noncustodial grandparents.

Research Question 4. The final research question is an inquiry into the relationships between custodial grandparents' needs, capabilities, and adaptability. Hypotheses 4, 5, and 6 addressed this final question.

According to the FAAR Model (Patterson, 1988, 1993), capabilities are what the family has to help them balance their needs. The outcome of the families' efforts to achieve balance between their demands and capabilities is conceptualized in terms of family adjustment or adaptation.

The results of the investigation into the relationship between the average custodial grandparents' needs and capabilities indicate that the relationship is not significant. In this study, the degree of helpfulness of the average custodial grandparents' capabilities does not predict the adequacy with which their needs

are met. Custodial grandparents who participated in this study have demands that are independent of their capabilities.

This finding is contrary to the FAAR Model and to previous research on parents of children with disabilities. Dyson and Fewell (1988); Frey, Fewell, and Vadasy (1989); and Frey, Greenberg, and Fewell (1989) noted that the greater the parents' capabilities, the less their needs.

A possible explanation for the absence of a relationship between custodial grandparents' demands and capabilities may be the limited scope of capabilities measured. The FNS measures the helpfulness of resources but does not measure coping behaviors. Patterson (1988, 1993) incorporates both resources and coping behaviors in the definition of capabilities and the operation of the FAAR Model.

Another explanation for the absence of a relationship between custodial grandparents' demands and capabilities may be the type or source of the capabilities of the custodial grandparents in this study. The scaled scores for the FNS and FSS indicate that the average custodial grandparents' needs are adequately met only half the time or less and their capabilities are not very helpful. The limited assistance of the custodial grandparents' capabilities, as well as the type of support and source of support, is also demonstrated in the grandparents' responses to open-ended questions.

Many of the grandparents explained that the reason they were raising their grandchildren was the substance abuse of the biological parent. The grandparents do not understand their children's behavior--child abuse, illegal activities, lack of emotional and financial support, enabling behaviors towards an abusive partner--that results from this substance abuse. The custodial grandparents received little, if any, financial, physical, or emotional support from

the custodial grandchildren's parents. The custodial grandparents' other children and family members were also not very helpful.

Their children's behavior and their role as custodial grandparents does not conform to the grandparents' norms of social conditions and behavior. When the grandparents look to social services for guidance on how to adjust to these new social conditions, they are asked to take over custodial caregiving responsibilities but have limited legal and financial support.

Custodial grandparents reported that they were informed that the grandchildren would go into foster care if the grandparent did not accept caregiving responsibilities. Many grandparents commented that they did not want strangers raising their grandchildren. Custodial grandparents also commented on the limited financial assistance they received from social services and the children's biological parents. There was much anger and frustration expressed by custodial grandparents about their inability to pay for daycare, clothing, toys, or other necessities for the grandchildren. Some grandparents noted that they would receive more from social services if they were foster parents rather than just grandparents. Other custodial grandparents commented that caring for their grandchildren was draining their savings or retirement accounts.

Another ambiguity custodial grandparents may experience is between boundaries or roles. Custodial grandparents and the grandchildren in their care may ask, "Who is the parent? Are the biological parents still the parent even though the grandparent is raising the grandchild?" When custodial grandparents look to the professional service agencies to help them interpret and understand these ambiguities they get mixed signals. On the one hand the courts have placed the grandchildren in the custodial grandparents' care but on the other hand the courts can return the grandchildren to their biological parent

at any time. Grandparents commented that the courts placed the rights of the parent over the rights of the children or grandparents.

Custodial grandparents in this study feared losing custody of their grandchildren. In response to open-ended questions, most grandparents reported that their greatest concern is their grandchildren's future safety and security. One custodial grandparent reported that when she complained to social services about the lack of financial support she was told that if it was too much of a hardship the grandchild could be taken out of the grandparent's home and placed in foster care.

Support for the custodial grandparents was also limited. Some of the grandchildren receive medical assistance through Children's Medical Services but most of the custodial grandparents commented they had difficulty paying for their own and their spouses' medical care. Custodial grandparents also lacked contact with other custodial grandparents who could act as a support network. Some custodial grandparents commented that they would like to talk to other grandparents to find out how they handled discipline problems with their grandchildren.

Taken together, the limited support from the custodial grandparents' subsystems, family system, and suprasystems may reduce the helpfulness of the custodial grandparents' capabilities in meeting their needs. The FAAR Model describes the effort to balance needs and capabilities as the first level of adaptation. The results of this investigation indicate that the average custodial grandparents' needs are independent of their capabilities. It appears that this component of the FAAR Model does not hold for the custodial grandparents in this study. Whether the remaining components of the FAAR Model hold for custodial grandparents is investigated in Hypotheses 5 and 6.

According to Patterson (1988, 1993) demands, or needs, are defined as the stimuli or conditions that produce or call for change in the family system. Sources of need can be from the personal subsystem, the family system and its subsystems, or the suprasystem levels. During adaptation, families may attempt to restore balance by reducing pileup of demands.

The results of the analysis for Hypothesis 5 indicate that, in this study, the relationship between the average custodial grandparents' perceptions of their needs and adaptation is significant. This indicates that how adequately the average custodial grandparents' needs are met is predictive of their total family adaptation.

Results from previous studies of custodial grandparents (Dressel & Barnhill, 1992; Minkler & Roe, 1993b; Minkler, Roe, & Price, 1992) also indicated a significant relationship between demands and adaptation. The custodial grandparents who had fewer unmet needs had better adaptation.

The discussions of the scaled scores for the FNS and the FACES II in Chapter Four and in the previous section of this chapter, as well as discussion of Hypotheses 1, 3, and 4, provide information about the number and spectrum of unmet needs experienced by custodial grandparents in this study and the resultant extreme family type. These results appear to support Patterson's (1988, 1993) explanation of the cycle of adjustment and adaptation and the role of family needs in this cycle.

The component of the FAAR Model addressing the relationship between family needs and adaptation holds for the custodial grandparents participating in this study. The final component of the model, the relationship between family capabilities and adaptation was addressed by Hypothesis 6.

According to the FAAR Model, capabilities consist of resources and coping behaviors that help families balance their needs (Patterson, 1988,

1993). Resources are available from the individual, subsystem, system, or suprasystem levels of the family system. During adaptation, families may attempt to restore balance by developing and acquiring new capabilities.

The results of the investigation into Hypothesis 6 indicate that the relationship between the average custodial grandparents' capabilities and adaptation is significant but weak. Indications are that the more helpful the average custodial grandparents, in this study, perceived their capabilities to be the better the grandparents perceived their family adaptation.

This finding supports the parental research of Crnic, Greenberg, Ragozin, Robinson, and Basham (1983), Dyson and Fewell (1988), Frey, Fewell, and Vadasy (1989), Frey, Greenberg, and Fewell (1989), Naseef (1989) and Paez (1992) that a significant relationship existed between family capabilities and adaptation. Parents of children with disabilities who had more helpful sources of support had better adaptation.

The discussion of the FSS and FACES II scaled scores in Chapter Four and previously in this chapter indicates limited helpfulness of the average custodial grandparents' capabilities, the spread of these capabilities across the family system levels, and the extreme family adaptation type of the average custodial grandparents in this study. The discussion of Hypotheses 2, 3, and 4 in this chapter also provides some insight into the dynamics of the custodial grandparents' capabilities and may explain the weakness of the significant relationship between capabilities and adaptation. Based on the investigation of Hypothesis 6, the component of the FAAR Model which addresses the direct relationship of family capabilities to adaptation holds for the custodial grandparents in this study.

Summary of Analyses for Hypotheses 1, 2, 3, 4, 5, and 6. The results of the investigation into custodial grandparents' nontraditional family structure

appear to support the tenets of Family Systems Theory operationalized by the FAAR Model, with the exception of a direct relationship between demands and capabilities. Although family capabilities do not affect family demands, both capabilities and demands affect family adaptation.

Based on the discussions of the number, type, and levels of family demands, capabilities, and adaptation as well as their relationships to each other, I would argue that Family Systems Theory seems to hold for the custodial grandparents raising young children with disabilities or at risk for disabilities who participated in this study.

#### Implications of the Research Findings

Family Systems Theory and the operational FAAR Model were the basis for this investigation into the relationship between grandparents' perceived demands, capabilities, and adaptation. The grandparent and grandchild characteristics that mediate the traditional grandparent-grandchild relationship were also investigated. The questions the study answered incorporated both the mediating characteristics, grandparents' perception of their demands, capabilities, and adaptation, and the relationships between and among these factors. The implications of the findings of this study for use of Family Systems Theory as operationalized by the FAAR Model in early intervention are discussed below.

The results of this study demonstrate that there are differences between parents and custodial grandparents of young children with disabilities or at risk for disabilities. One important aspect of custodial grandparents' differences is the stress many custodial grandparents feel due to their uncertain legal status as custodial caregivers. Custodial grandparents may hesitate to become actively involved in early intervention programs because they are not sure of the length of time they will be caring for their grandchildren. Custodial grandparent



may also be unsure whether they can legally agree to or participate in early intervention programs. Early interventionists need to be familiar with the legal rights, or have access to information addressing the legal rights, of custodial grandparents regarding early intervention planning and implementation.

Best practices, although not common practice, in early intervention are family centered (Dunst, Trivette, & Deal, 1988). Family centered practices reflect Family Systems Theory in that the child is recognized and served as part of the family. Family centered practices acknowledge and consider the effect the child has on the family and the effect the family has on the child. In their efforts to implement family centered programs, early interventionists develop IFSPs and IEPs that address child and family goals (Individuals with Disabilities Education Act, 1990).

The findings that, for this sample, the average custodial grandparents' needs and capabilities are independent of each other but are related to the custodial grandparents' total family adaptation indicate that family goals should focus on the both custodial grandparents' needs and capabilities. Currently, early interventionists tend to focus on parent or family needs and fail to address the parent or family capabilities (Dunst & Trivette, 1987).

Another component of family centered intervention is family empowerment. An empowered family is one that recognizes its needs and capabilities and has the knowledge and skills to access the resources the family needs to adapt. A family empowerment model has interventionists working with families to identify the families' demands and capabilities, the methods with which the families currently accesses their capabilities, and strategies to improve these methods. A family empowerment model also provide families with practice on the strategies and support as the families incorporate these new strategies into their repertoire of skills (Dunst & Trivett, 1987; Hughes,

1987; Kopp, 1989). The relationships between custodial grandparents' demands and adaptation and between their capabilities and adaptation indicate that the empowerment model is appropriate for use with custodial grandparents.

A method of working with custodial families to identify their demands and capabilities is family assessment. The system levels at which the custodial grandparents experience their needs and capabilities and the types and quality of transactions among these levels should also be assessed by the early interventionists and the custodial grandparents jointly. Early interventionists may find it helpful to develop an ECOMap with the custodial grandparents. This map graphically illustrates the family's subsystems and suprasystems, and the direction and quality of transactions between system components. Such a map would help both the early interventionists and the custodial grandparents to understand and conceptualize the custodial grandparents' family system, begin discussion on capabilities and methods of accessing the capabilities, and enhance family centered programming and family empowerment.

#### Limitations to the Present Study

The results obtained in this study may be limited due to several factors. First, the small sample size ( $n=93$ ) and return rate (25%), while not prohibitive, are problematic. The small return rate precludes valid generalization of the results of this investigation beyond the custodial grandparents who participated in the study. Second, the mediating factors used as independent characteristics were a result of a literature search on traditional grandparent-grandchild relationships. Only those factors that were documented in previous studies as affecting the grandparent-grandchild relationship were included as independent variables. Other potentially mediating independent factors were not investigated in this study. Examples of such factors include other people in

the home, their ages and role(s), the involvement of the grandchildren's parents in family activities and childcare, the status of the child's parents' relationship with the custodial grandparents; the length of time the grandparents have had custody; the status of the relationship with the grandchild--legal custody versus full-time caretaking versus part-time caretaking--and the grandchild's diagnosed disability or at risk condition. These factors, which were present in this study, may have had a mediating effect on the outcomes of this investigation.

Finally, only one type of nontraditional family structure was investigated in this study. Therefore, implications of this study for Family Systems Theory as operationalized by the FAAR Model cannot be generalized to other nontraditional families such as single parent; foster; adoptive; custodial great-grandparent; custodial aunt, uncle or sibling; and gay or lesbian families.

Limitations related to the instruments used in this study also exist. First, this study is limited by use of self-report scales, which are susceptible to respondent bias. Grandparents may not have responded to items they considered intrusive or embarrassing. Grandparents may have scored an item higher or lower than they truly perceived it to be because they perceived the false score to be "best." Grandparents may have projected what they thought the study was about and chosen responses that reflected that projection. The custodial grandparents who participated in this study may not have trusted the anonymity of their responses and selected responses that they perceived as "correct."

Second, limited psychometric information was available for some of the family assessment scales used in this study. The FNS and FSS had limited published validity and reliability data on the domains identified through factor analysis. However, to address this problem the data from this study were used

to establish internal consistency for each instrument and the total scaled scores, only, were used as dependent variables.

### Recommendations for Future Research

To reflect the changing demographics of our early intervention programs and service sites, family research must reflect the changing demographics of families. Replicating this type of study to include a representative sample of custodial grandparents as well as other nontraditional families is recommended. This replication would provide insight into the family systems and adaptation of a variety of family structures. A variation of this study would be to include independent variables related to the grandchild's disability or at risk status as well as other potential mediating factors not included in this study.

I also recommend investigating custodial grandparents' needs, capabilities, and adaptation as a longitudinal study across the family life cycle. Investigating the changes in or progression of needs, capabilities, and adaptation of grandparents raising young grandchildren with disabilities or at risk for disabilities from the beginning of primary caregiving responsibilities through typical developmental changes and major stress events can provide information for early interventionists and other service providers at each stage of the developmental cycle. Such an investigation would also provide information regarding the complete adjustment and adaptation process rather than a segment of the process.

Finally, to enhance the practitioner's understanding of family functioning, future researchers should use a combination of qualitative and quantitative methods to investigate family functioning. A combination of research methodology may provide practitioners with specific techniques for facilitating family focused interventions as well as information regarding the specific components involved in their functioning.

### Summary

This study was conducted to challenge the Family Systems Theory operationalized by the FAAR Model with a nontraditional family type; i.e. custodial grandparents of young children with disabilities or at risk for disabilities. To do this I investigated the relationship between custodial grandparents' perceptions of their needs, capabilities, and adaptation. Relationships between certain grandparent and grandchild characteristics and the custodial grandparents' needs, capabilities, and adaptation were also investigated. Results of this study indicate the absence of relationships between the grandparent and grandchild characteristics, in total, and the custodial grandparents' needs and their capabilities. There is, however, a relationship between grandparent and grandchild characteristics, in total, and the average custodial grandparents' adaptation.

Results from this study also indicate that the average custodial grandparents' capabilities and needs are independent of each other. This finding is contrary to the FAAR Model which states that capabilities are used to balance demands. However, there is a relationship between custodial grandparents' capabilities and adaptation and between their needs and their adaptation.

The average custodial grandparents participating in this study identified needs in all domains of the FNS. Custodial grandparents received limited assistance in meeting their needs. Indeed, responses to the FSS indicate that custodial grandparents were isolated from their family, friends, spouse or partner's family, and social organizations. Although all the grandparents who participated in this study received some assistance from professional services, many custodial grandparents remarked on how inadequate this assistance was, especially financially. Nor were the parents of the custodial grandchildren of

assistance to the custodial grandparent. Most custodial grandparents noted that they were raising their grandchildren because the parents of the grandchildren were abusing alcohol or drugs, were abusive parents or spouses, or were in trouble with the law. The custodial grandparents accepted custody of the grandchildren rather than have the grandchildren go to "strangers".

Custodial grandparents remarked on how much they loved their grandchildren, enjoyed seeing them laugh and learn but worried about their future and what would happen when the grandchildren were no longer in their custody or the grandparents were no longer able to care for the grandchildren. Even though they expressed their love for their grandchildren, some custodial grandparents remarked that they had not planned to be raising their grandchildren and it was a role they would prefer not to perform.

The ambiguity between the custodial grandparents' expectations and their reality may be reflected in the expectations of other family members and social organizations. Social ambiguity can lead to difficulties in the custodial grandparents' adaptation to their current realities. The custodial grandparents' responses to the FACES II indicate that they are functioning as extreme family types. Results of this investigation into custodial grandparents raising young children with disabilities or at risk for disabilities indicate that they are a heterogeneous and different population with a range of needs, capabilities and adaptation.

This investigation into Family Systems Theory and the FAAR Model in relation to the custodial grandparent family revealed that the custodial grandparents' needs and capabilities interact with their adaptation. When working with families, it is not enough to identify their needs. Early interventionists must also identify the family's current capabilities and the

direction and quality of interactions between the levels of the custodial grandparents' family system. Early interventionists may need to assist the custodial grandparents in enhancing and expanding their capabilities and the communication within the family system. In this study, grandparent and grandchild characteristics, the average custodial grandparents' needs and their capabilities affected their adaptation.

APPENDIX A  
LIST OF CONTACTS



## Grandparent Organizations

Mental Health Association  
5546 W. Oakland Park  
Boulevard, Suite 207  
Lauderhill, FL 33313

Grandparents Raising Grandchildren  
1425 Pecan Street  
Nokomis, FL 34275

Grandparent Support Group  
183 Garden Avenue  
Port Charlotte, FL 33952

Family Counseling Center  
3205 S. Gate Court  
Sarasota, FL 34239

Recycled Parents  
P.O. Box 5142  
Salt Springs, FL 32134

Grandparent Support Group  
10350 St. Patricks Lane  
Bonita Springs, FL 33923

Grandparents Rights Advocacy  
Movement, Inc. (GRAM)  
Box 523  
Tarpon Springs, FL 34688

GRAM  
5517 Magnolia Way  
New Port Richie, FL 34652

Concerned Grandparents, Inc.  
1001 Carlton Street  
Clearwater, FL 34615

Grandparent Support Group  
1679 Holiday Drive  
Orlando, FL 32707

"Second Chance" Coalition  
St. Petersburg Free Clinic, Inc..  
863 Third Avenue North  
St. Petersburg, FL 33701

Grandparent Support Group  
4015 Windtree Road  
Tampa, FL 33624

Grandparent Support Group of Ocala,  
Florida  
20945 S.E. 156th Street  
Umatilla, FL 32784

Grandparents Raising Grandchildren  
2748 NW 9th Terrace  
Wilton Manor, FL 33311

Grandparents Helping Grandparents  
863 3rd Ave. N.  
St. Petersburg, FL 33701

Intergenerational Day Care/Respite  
NE Focal Point Senior Center  
227 NW 2nd Street  
Deerfield, FL 33441

GRAM (Hispanic)  
P.O. Box 360052  
Tampa, FL 33673

Elderly and Pediatrics Team Nursing  
Service  
1459 S. University Drive  
Plantation, FL 33324

Grandparent Support Group  
2621 Saratoga Place  
Deland, FL 32720

Grandparents United  
c/o HRS District 04  
Jacksonville, FL

## HRS Districts

<u>DIST</u>	<u>DISTRICT ADDRESS</u>	<u>DIST</u>	<u>DISTRICT ADDRESS</u>
01	160 Governmental Center P.O. Box 12836 Pensacola, FL 32505-8420	09	111 Georgia Avenue West Palm Beach, FL 33401
02	Cedars Executive Center 2639 North Monroe Street Suite 200A Tallahassee, FL 3203	10	Broward Reg. Services Center 201 West Broward Blvd. Ft. Lauderdale, FL 33301
03	1000 NE 16th Avenue Building HSC 625-5010 Gainesville, FL 32609-4598	11	401 N.W. Second Avenue Room 1007, North Tower Miami, FL 33128
04	5920 Arlington Expressway P.O. Box 2417F Jacksonville, FL 32231	12	Daytona Beach Service Center 210 N. Palmetto Avenue Daytona Beach, FL 32114
05	11351 Ulmerton Road Largo, FL 34648-1630	13	3001 W. Silver Springs Blvd. Ocala, FL 32675-5699
06	4000 W. Martin Luther King Jr. Blvd. Tampa, FL 33614	14	2020 East Georgia St. Bartow, FL 33830
07	400 West Robinson Street Suite 1129, South Tower Orlando, FL 32801	15	1802 Okeechobee Road Ft. Pierce, FL 43950
08	8695 College Parkway P.O. Box 06085 Ft. Myers, FL 33906		

APPENDIX B  
SURVEY PACKET

June 1, 1994

Dear Grandparents;

I am Cheryl Beverly, a student at the University of Florida. I am studying grandparents who are currently raising children younger than five years of age. I am particularly interested in grandparents with grandchildren who are disabled or who have experienced prenatal, physical, emotional, or environmental problems. I believe it is important for teachers, as well as other people who work with young children, to understand the important role of the family in the young child's life. I also believe that we need to think of families as more than just two parents and their children. For this reason I am studying families that include grandparents who are raising their grandchildren. I want to understand the areas grandparent's need help in when caring for their grandchildren. I also want to understand who grandparents get help from and how they solve the problems they have when raising young grandchildren. Finally, I would like to learn how grandparents adapt to their family's situation. Understanding all this will help me teach teachers and other people who work with families and young children. I hope that knowing about grandparents who are caring for their grandchildren can help all of us to plan better programs and services for young children. This may also help us to know what needs to be done to help grandparents who are raising grandchildren and the best ways to work with them.

I am currently doing a study to gather this type of information. I would like to include your family in this study. If you would like to help me, I ask that you answer the questions in the enclosed booklet. The booklet includes a general information survey and three questionnaires: the Family Demands Scale, the Family Capabilities Scale, and the Family Adaptation and Cohesion Evaluation Scale II. There may be questions that do not apply to your family, please leave them blank. If there are any questions you do not want to answer you may also leave them blank. After you have answered the questions please return the booklet to me in the enclosed self addressed stamped envelope.

Although there are no immediate benefits for your young grandchild or family, this information will help teachers and others in understanding grandparents raising young grandchildren. It will also help us to have better partnerships with them. Any information you provide in this study will be used in a professional manner for educational purposes. Your name and personal information will remain confidential. Your name will not be on the answer booklet. I have assigned an identification number to each booklet. The identification number is for follow-up purposes only. After a few weeks, if I have not received your

booklet a reminder follow-up post-card will be mailed. At the end of the data collection, about eight weeks, the identification list will be destroyed. This means that no one will be able to match your answers with your name.

You are, of course, free to withdraw your participation in this study at any time. If you have any questions or concerns regarding this study please feel free to contact me at 904-392-0701 extension 300, or write me at University of Florida, Norman Hall, Room G-315, Gainesville, Florida 32611.

If you are willing to help me with this study please complete all the forms in this booklet and return them in the self addressed stamped envelope provided for your use. In an effort to ensure your privacy, I will not be collecting written consent from you, but will use the returned packet as an indication of permission to use the information in my study.

Thank you for your help in this study. You are helping me to help your grandchildren and other grandchildren.

Cheryl L. Beverly

## Grandparents Raising Young Grandchildren

Cheryl L. Beverly  
University of Florida  
Norman Hall, G-315  
Gainesville, Florida 32611  
(904) 392-0701 ext. 300

Confidential Identification Code \_\_\_\_\_

**Family Needs Scale**  
(Dunst, Cooper, Weeldreyer, Snyder, & Chase, 1988)

This scale asks if you or your family have a need for any type of help in the areas named. Circle the number in the scale next to each item that best describes the type of help your family receives.

<b>Almost Never</b> 1	<b>Seldom A Few Times</b> 2	<b>Sometimes Half the Time</b> 3	<b>Often</b> 4	<b>Almost Always</b> 5
To what extent does your family get these types of help?			To what extent does your family get these types of help?	
1. Having money to buy necessities	1 2 3 4 5	21. Planning for future of my grandchild		1 2 3 4 5
2. Having money to pay bills	1 2 3 4 5	22. Getting where I need to go		1 2 3 4 5
3. Budgeting money	1 2 3 4 5	23. Contacting people I need to talk to		1 2 3 4 5
4. Paying for special needs of my grandchild	1 2 3 4 5	24. Transporting my grandchild		1 2 3 4 5
5. Saving money for the future	1 2 3 4 5	25. Having special travel equipment for my grandchild		1 2 3 4 5
6. Having clean water	1 2 3 4 5	26. Finding someone to talk to about my grandchild		1 2 3 4 5
7. Having food for my family	1 2 3 4 5	27. Having someone to talk to		1 2 3 4 5
8. Having time to cook healthy meals for my family	1 2 3 4 5	28. Having medical care for my family		1 2 3 4 5
9. Feeding my grandchild	1 2 3 4 5	29. Having dental care for my family		1 2 3 4 5
10. Getting a place to live	1 2 3 4 5	30. Having time to take care of myself		1 2 3 4 5
11. Having water	1 2 3 4 5	31. Having emergency health care		1 2 3 4 5
12. Having electricity	1 2 3 4 5	32. Finding special dental care for my grandchild		1 2 3 4 5
13. Having heat	1 2 3 4 5	33. Finding medical care for my grandchild		1 2 3 4 5
14. Getting furniture	1 2 3 4 5	34. Planning for future health need		1 2 3 4 5
15. Getting clothes	1 2 3 4 5	35. Managing the daily needs of my grandchild at home		1 2 3 4 5
16. Getting toys	1 2 3 4 5	36. Caring for my grandchild during work hours		1 2 3 4 5
17. Completing chores, repairs, home improvements	1 2 3 4 5			
18. Adapting my home for my grandchild	1 2 3 4 5			
19. Getting or keeping a job	1 2 3 4 5			
20. Having a satisfying job	1 2 3 4 5			

### Family Needs Scale--continued

Please circle the number in the scale next to each item that best describes the type of help your family needs.

Almost Never	Seldom A Few Times	Sometimes Half the Time	Often	Almost Always
1	2	3	4	5

To what extent does your family get these types of help?

To what extent does your family get these types of help?

- |   |  |
|---|--|
| 37. Having emergency child care      1 2 3 4 5<br>38. Getting time to myself away from my grandchild      1 2 3 4 5<br>39. Finding care for my grandchild in the future      1 2 3 4 5<br>40. Finding a school placement for my grandchild      1 2 3 4 5<br>41. Getting equipment for my grandchild      1 2 3 4 5<br>42. Getting therapy for my grandchild      1 2 3 4 5 | 43. Having time to take my grandchild to appointments      1 2 3 4 5<br>44. Exploring future educational options for my grandchild      1 2 3 4 5<br>45. Expanding my education, skills, and interests      1 2 3 4 5<br>46. Doing things that I enjoy      1 2 3 4 5<br>47. Doing things with my family      1 2 3 4 5<br>48. Participating in groups or activities      1 2 3 4 5<br>49. Traveling/vacationing with my grandchild      1 2 3 4 5 |
|---|--|

Use this space to write anything else you would like to tell me about anything your family's needs to help you care for your young grandchildren.

I would also like to know what you enjoy about caring for your young grandchildren.



# Family Support Scale (Dunst, Trivette, & Jenkins, 1988)

This scale asks about the people and groups that are sometimes helpful to members of your family. Circle the number in the scale next to each item that best indicates how helpful each source is for you and your family during the past 3 to 6 months. If a source has not been available to you do not circle a response.

Not at All Helpful 1	Helpful A Few Times 2	Helpful Half the Time 3	Very Helpful 4	Extremely Helpful 5
----------------------------	-----------------------------	-------------------------------	-------------------	---------------------------

How helpful has each source been in terms of raising your grandchild?

How helpful has each source been in terms of raising your grandchild?

- |   |           |   |           |
|---|-----------|---|-----------|
| 1. My parents                           | 1 2 3 4 5 | 12. My co-workers   | 1 2 3 4 5 |
| 2. My spouse/partner's parents          | 1 2 3 4 5 | 13. Parent groups   | 1 2 3 4 5 |
| 3. My relatives or kin                  | 1 2 3 4 5 | 14. Grandparent groups  | 1 2 3 4 5 |
| 4. My children                          | 1 2 3 4 5 | 15. Social groups/clubs   | 1 2 3 4 5 |
| 5. My spouse/partner's relatives or kin | 1 2 3 4 5 | 16. Church members or ministers   | 1 2 3 4 5 |
| 6. My spouse/partner's children         | 1 2 3 4   | 17. My physician  | 1 2 3 4 5 |
| 7. My spouse/partner                    | 1 2 3 4 5 | 18. My grandchild's physician   | 1 2 3 4 5 |
| 8. My friends                           | 1 2 3 4 5 | 19. Early childhood intervention program  | 1 2 3 4 5 |
| 9. My spouse/partner's friends          | 1 2 3 4   | 20. School/day care program   | 1 2 3 4 5 |
| 10. Other parents                       | 1 2 3 4 5 | 21. Professional helpers (social workers, therapists, teachers, etc.)           | 1 2 3 4 5 |
| 11. Other grandparents                  | 1 2 3 4 5 | 22. Professional agencies (public health, social services, mental health, etc.) | 1 2 3 4 5 |

Are there any other things you do that help you to raise your grandchild that you would like to share?

## FACES II: Family Version (Olson, Portner & Bell)

Please read each statement and decide on the answer that best describes how frequently the behavior occurs in your family. Circle the most appropriate response.

<b>Almost Never</b>	<b>Once in Awhile</b>	<b>Sometimes</b>	<b>Frequently</b>	<b>Almost Always</b>
1	2	3	4	5
How frequently does the described behavior occur in your family?			How frequently does the described behavior occur in your family?	
1. Family members are supportive of each other during difficult times	1 2 3 4 5		16. In solving problems, the grandchildren's suggestions are followed	1 2 3 4 5
2. In our family, it is easy for everyone to express his/her opinion	1 2 3 4 5		17. Family members feel very close to each other	1 2 3 4 5
3. It is easier to discuss problems with people outside the family than with other family members	1 2 3 4 5		18. Discipline is fair in our family	1 2 3 4 5
4. Each family member has input regarding major family decisions	1 2 3 4 5		19. Family members feel closer to people outside the family than to other family members	1 2 3 4 5
5. Our family gathers together in the same room	1 2 3 4 5		20. Our family tries new ways of dealing with problems	1 2 3 4 5
6. Grandchildren have a say in their discipline	1 2 3 4 5		21. Family members go along with what the family decides to do	1 2 3 4 5
7. Our family does things together	1 2 3 4 5		22. In our family, everyone shares responsibilities	1 2 3 4 5
8. Family members discuss problems and feel good about the solutions	1 2 3 4 5		23. Family members like to spend their free time with each other	1 2 3 4 5
9. In our family, everyone goes his/her own way	1 2 3 4 5		24. It is difficult to get a rule changed in our family	1 2 3 4 5
10. We shift household responsibilities from person to person	1 2 3 4 5		25. Family members avoid each other at home	1 2 3 4 5
11. Family members know each other's close friends	1 2 3 4 5		26. When problems arise, we compromise	1 2 3 4 5
12. It is hard to know what the rules are in our family	1 2 3 4 5		27. We approve of each other's friends	1 2 3 4 5
13. Family members consult other family members on personal decisions	1 2 3 4 5		28. Family members are afraid to say what is on their minds	1 2 3 4 5
14. Family members say what they want	1 2 3 4 5		29. Family members pair up rather than do things as a total family	1 2 3 4 5
15. We have difficulty thinking of things to do as a family	1 2 3 4 5		30. Family members share interests and hobbies with each other	1 2 3 4 5

## GRANDPARENT(S) INFORMATION

The following information will help me to understand grandparents who are raising grandchildren. Please answer each question in the space provided next to it. When more than one possible answer is listed, please put a check (✓) next to each correct answer. **Today's date is** \_\_\_\_\_

1. How many grandchildren are you raising who are younger than five years of age? \_\_\_\_\_
2. What is your gender?  
MALE \_\_\_\_\_ FEMALE \_\_\_\_\_
3. What is your marital status?  
MARRIED \_\_\_\_\_  
DIVORCED/SEPARATED \_\_\_\_\_  
WIDOWED \_\_\_\_\_  
REMARRIED \_\_\_\_\_  
LIVING WITH A PARTNER \_\_\_\_\_
4. What is your date of birth?  
(month, day, year) \_\_\_\_\_
5. How is your health?  
EXCELLENT \_\_\_\_\_  
GOOD \_\_\_\_\_  
O.K. \_\_\_\_\_  
POOR \_\_\_\_\_
6. What is your race/ethnicity? \_\_\_\_\_
7. What is your employment status:  
RETIRED \_\_\_\_\_  
EMPLOYED (FULL TIME) \_\_\_\_\_  
EMPLOYED (PART TIME) \_\_\_\_\_  
UNEMPLOYED \_\_\_\_\_  
DISABLED \_\_\_\_\_
8. What is your occupation? \_\_\_\_\_
9. What is your spouse/partners date of birth?  
(month, day, year) \_\_\_\_\_
10. How is your spouse/partner's health?  
EXCELLENT \_\_\_\_\_  
GOOD \_\_\_\_\_  
O.K. \_\_\_\_\_  
POOR \_\_\_\_\_
11. What is your spouse/partner's race/ethnicity? \_\_\_\_\_
12. What is your spouse/partner's employment status:  
RETIRED \_\_\_\_\_  
EMPLOYED (FULL TIME) \_\_\_\_\_  
EMPLOYED (PART TIME) \_\_\_\_\_  
UNEMPLOYED \_\_\_\_\_  
DISABLED \_\_\_\_\_
13. What is your spouse/partner's occupation? \_\_\_\_\_
14. What is your family's annual income?  
BELOW \$5,000.00 \_\_\_\_\_  
\$5,000. - \$9,999. \_\_\_\_\_  
\$10,000. - \$19,999. \_\_\_\_\_  
\$20,000. - \$29,999. \_\_\_\_\_  
\$30,000. - \$40,000. \_\_\_\_\_  
ABOVE \$40,000. \_\_\_\_\_
15. What type of home do you live in?  
OWN HOUSE \_\_\_\_\_  
RENT HOUSE \_\_\_\_\_  
APARTMENT \_\_\_\_\_  
OTHER \_\_\_\_\_
16. Where is your home located?  
COUNTRY \_\_\_\_\_  
CITY \_\_\_\_\_  
SUBURBS \_\_\_\_\_  
OTHER \_\_\_\_\_
17. Are you caring for anyone who is not a grandchild?  
YES \_\_\_\_\_ NO \_\_\_\_\_
18. What is this person's relationship to you?  
PARENT \_\_\_\_\_  
CHILD \_\_\_\_\_  
SIBLING \_\_\_\_\_  
OTHER \_\_\_\_\_

Please answer each question in the space provided next to it.

19. What are the major things you worry about related to raising your grandchildren?

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20. Is there anything else you would like to mention about yourself, your spouse/partner, or your family?

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Is there anything else about yourself, your spouse, or your family you would like to share?

## GRANDCHILD #1 INFORMATION

Please provide the following information for any grandchild who is younger than 5 years of age and you are raising. If you are raising more than one grandchild, please complete one page for each grandchild. Please provide the information requested in the blank next to each answer. When more than one possible answer is listed, please put a check (✓) next to each correct answer.

- |  |  |
|--|--|
| <p>1. What is your grandchild's birthrate?<br/>(month, day, year)_____</p> <p>2. What is your grandchild's gender?<br/>MALE_____ FEMALE_____</p> <p>3. What is your relationship to your<br/>grandchild?<br/>MY SON'S CHILD _____<br/>MY DAUGHTER'S CHILD _____<br/>OTHER _____</p> <p>4. What is your grandchild's race/ethnicity?<br/>_____</p> <p>5. Does your grandchild have a diagnosed<br/>disability?<br/>YES_____ NO_____</p> <p>6. If yes, what is your grandchild's<br/>disability?<br/>DEVELOPMENTAL DELAY _____<br/>MENTALLY RETARDED _____<br/>VISION _____<br/>PHYSICALLY HANDICAPPED _____<br/>EMOTIONAL/BEHAVIOR _____<br/>DISABLED _____<br/>HEARING _____<br/>LEARNING DISABLED _____<br/>OTHER _____</p> | <p>7. What were the reasons you decided to<br/>raise your grandchild?<br/>_____<br/>_____<br/>_____<br/>_____</p> <p>8. Do you still have contact with the<br/>parent(s) of the grandchild you are<br/>raising?<br/>YES_____ NO_____</p> <p>9. How would you describe your relationship<br/>with the parents of the grandchildren you<br/>are raising?<br/>VERY GOOD _____<br/>GOOD _____<br/>SATISFACTORY _____<br/>POOR _____<br/>VERY POOR _____</p> <p>10. Do you receive any help from the parent(s)<br/>of the grandchild you are raising?<br/>YES_____ NO_____</p> <p>11. If yes, what type of help do you receive?<br/>_____<br/>_____<br/>_____<br/>_____</p> |
|--|--|

Is there anything else you would like to share about your experiences raising this grandchild?

## GRANDCHILD #2 INFORMATION

Please provide the following information for any grandchild who is younger than 5 years of age and you are raising. If you are raising more than one grandchild, please complete one page for each grandchild. Please provide the information requested in the blank next to each answer. When more than one possible answer is listed, please put a check ( ✓ ) next to each correct answer.

- |  |   |
|--|---|
| <p>1. What is your grandchild's birthrate?<br/>(month, day, year)_____</p> <p>2. What is your grandchild's gender?<br/>MALE_____ FEMALE_____</p> <p>3. What is your relationship to your grandchild?<br/>MY SON'S CHILD_____<br/>MY DAUGHTER'S CHILD_____<br/>OTHER_____</p> <p>4. What is your grandchild's race/ethnicity?<br/>_____</p> <p>5. Does your grandchild have a diagnosed disability?<br/>YES_____ NO_____</p> <p>6. If yes, what is your grandchild's disability?<br/>DEVELOPMENTAL DELAY_____<br/>MENTALLY RETARDED_____<br/>VISION_____<br/>PHYSICALLY HANDICAPPED_____<br/>EMOTIONAL/BEHAVIOR_____<br/>DISABLED_____<br/>HEARING_____<br/>LEARNING DISABLED_____<br/>OTHER_____</p> | <p>7. What were the reasons you decided to raise your grandchild?<br/>_____<br/>_____<br/>_____<br/>_____</p> <p>8. Do you still have contact with the parent(s) of the grandchild you are raising?<br/>YES_____ NO_____</p> <p>9. How would you describe your relationship with the parents of the grandchildren you are raising?<br/>VERY GOOD_____<br/>GOOD_____<br/>SATISFACTORY_____<br/>POOR_____<br/>VERY POOR_____</p> <p>10. Do you receive any help from the parent(s) of the grandchild you are raising?<br/>YES_____ NO_____</p> <p>11. If yes, what type of help do you receive?<br/>_____<br/>_____<br/>_____</p> |
|--|---|

Is there anything else you would like to share about your experiences raising this grandchild?

### GRANDCHILD #3 INFORMATION

Please provide the following information for any grandchild who is younger than 5 years of age and you are raising. If you are raising more than one grandchild, please complete one page for each grandchild. Please provide the information requested in the blank next to each answer. When more than one possible answer is listed, please put a check ( ✓ ) next to each correct answer.

1. What is your grandchild's birthrate?  
(month, day, year)\_\_\_\_\_
2. What is your grandchild's gender?  
MALE\_\_\_\_\_FEMALE\_\_\_\_\_
3. What is your relationship to your grandchild?  
MY SON'S CHILD \_\_\_\_\_  
MY DAUGHTER'S CHILD \_\_\_\_\_  
OTHER \_\_\_\_\_
4. What is your grandchild's race/ethnicity?  
\_\_\_\_\_
5. Does your grandchild have a diagnosed disability?  
YES\_\_\_\_\_ NO \_\_\_\_\_
6. If yes, what is your grandchild's disability?  
DEVELOPMENTAL DELAY \_\_\_\_\_  
MENTALLY RETARDED \_\_\_\_\_  
VISION \_\_\_\_\_  
PHYSICALLY HANDICAPPED \_\_\_\_\_  
EMOTIONAL/BEHAVIOR \_\_\_\_\_  
DISABLED \_\_\_\_\_  
HEARING \_\_\_\_\_  
LEARNING DISABLED \_\_\_\_\_  
OTHER \_\_\_\_\_
7. What were the reasons you decided to raise your grandchild?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
8. Do you still have contact with the parent(s) of the grandchild you are raising?  
YES\_\_\_\_\_ NO \_\_\_\_\_
9. How would you describe your relationship with the parents of the grandchildren you are raising?  
VERY GOOD \_\_\_\_\_  
GOOD \_\_\_\_\_  
SATISFACTORY \_\_\_\_\_  
POOR \_\_\_\_\_  
VERY POOR \_\_\_\_\_
10. Do you receive any help from the parent(s) of the grandchild you are raising?  
YES\_\_\_\_\_ NO \_\_\_\_\_
11. If yes, what type of help do you receive?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Is there anything else you would like to share about your experiences raising this grandchild?

Dear Grandparents,

Thank you for taking the time to answer these questions. Please return the survey to me in the self-addressed stamped envelop that was included with the survey. If you would like to make additional comments regarding these questions or your experiences raising your grandchildren, please use the remainder of this space to do so. Your answers will help me to understand grandparents who are raising young grandchildren. I will use this information to help me train teachers who may be working with other grandparents who are raising their young grandchildren.

Sincerely,

Cheryl L. Beverly



### Reminder Postcard

Your completed survey packet entitled "Grandparents Raising Young Grandchildren" has not been received. If you have already returned it, thank you for your help. If you have not returned it, please take the time to do so. I really appreciate your help in this matter. If you have any questions please feel free to contact me.

Thank you,  
Cheryl L. Beverly  
University of Florida  
Norman Hall, G-315  
Gainesville, Florida 32611  
(904) 392 - 0701 ext. 300

August 8, 1994

Dear Grandparents;

I recently sent you a letter asking for your help collecting information about grandparents who are raising their grandchildren. Along with the letter I sent a booklet of questions about the things you need help with, the types of help you get and how your family is coping with your experiences. I am sending you another copy of the booklet of questions and a stamped, addressed return envelope. It is very important that I learn as much as possible about the experiences of grandparents who are raising young grandchildren. Grandparents who are caring for their grandchildren are a special group of people, the information you provide me is unique to your family.

I realize how busy you must be but hope that you will take the time to answer the questions and return the booklet to me. You are an important part of my study, the information you can provide is very valuable. The information you provide can help me to teach teachers and other persons how to better understand and work with grandparents and grandchildren, as well as other families. You do not need to worry about anyone tracking your answers back to you. Your name or address is not written on the booklets.

If there are any questions that do not apply to your family, you may leave them blank. If there are any questions you do not want to answer you may also leave them blank. You may also withdraw your participation in this study at any time. If you have any questions or concerns about the booklet or the study please feel free to contact me at 904-392-0701 ext. 300. If I am not there the secretary will take a message and I will call you back as soon as I can.

Once again please consider helping me with this study. This information may help other grandparents and grandchildren.

Sincerely,

Cheryl Beverly

APPENDIX C  
CODES FOR INDEPENDENT VARIABLES

## GRANDPARENT(S) INFORMATION CODES

2. What is your gender?
  - 1 = male
  - 2 = female
3. What is your marital status?
  - 1 = married
  - 2 = divorced/separated
  - 3 = widowed
  - 4 = remarried
  - 5 = living with a partner
  - 6 = single
4. What is your date of birth?  
age in number of years
5. How is your health?
  - 1 = excellent
  - 2 = good
  - 3 = o.k.
  - 4 = poor
6. What is your race?
  - 1 = Caucasian
  - 2 = African-American
  - 3 = Hispanic
  - 4 = Hispanic
  - 5 = American Indian
  - 6 = Bi-racial
7. What is your employment status?
  - 1 = retired
  - 2 = employed (full time)
  - 3 = employed (part time)
  - 4 = unemployed
  - 5 = disabled
  - 6 = student
14. What is your family's annual income?
  1. = below \$5,000.00
  2. = \$5,000-\$9,999
  - 3 = \$10,000-\$19,999.
  - 4 = \$20,000-\$29,999.
  - 5 = \$30,000-\$39,999.
  - 6 = above \$40,000.

## GRANDCHILD INFORMATION CODE

1. What is your grandchild's birthdate?  
age in number of years
2. What is your grandchild's gender?  
1 = male  
2 = female
3. What is your relationship to your grandchild?  
1 = my son's child  
2 = my daughter's child  
3 = other
4. What is your grandchild's race/ethnicity?  
1 = Caucasian  
2 = African-American  
3 = Hispanic  
4 = Hispanic  
5 = American Indian  
6 = Bi-racial
6. What is your grandchild's disability?  
1 = yes  
2 = no  
3 = speech  
4 = respiratory problems  
5 = shunt  
6 = physical health problems  
7 = heart problems  
8 = abuse (physical, emotional, sexual)  
9 = "cocaine baby"  
10=failure to thrive  
11=hyperactive
8. Do you still have contact with the parents?  
1=yes  
2=no
9. Relationship with the parents (their child) of the grandchildren?  
1=very good  
2=good  
3=satisfactory  
4=poor  
5=very poor
10. Do you receive any help from the parents?  
1=yes  
2=no

APPENDIX D  
FACES II: LINEAR SCORING & INTERPRETATION

FACES II: Linear Scoring & Interpretation Guidelines  
Olson, D. H., Bell, R. Q., & Portner, J. (1991)

Coesion		Adaptability			Family Type	
8	80	Very Connected	8	70	Very Flexible	Balanced
7	74		7	65		
	73			64		
	71			55		
6	70	Connected	6	54	Flexible	Moderately Balanced
5	65		5	50		
	64			49		
	60			46		
4	59	Separated	4	45	Structured	Mid-Range
3	55		3	43		
	54			42		
	51			40		
2	50	Disengaged	2	39	Rigid	Extreme
1	35		1	30		
	34			29		
	15			15		

\_\_\_ Cohesion + \_\_\_ Adaptability \_\_\_/2 = Type

# Circumplex Model for Interpreting FACES II Olson (1993)

		Low-----	-----	COHESION	-----High			
High	F L E X I B I L I T Y	Chaotically Disengaged	Chaotically Separated	Chaotically Connected	Chaotically Enmeshed	Levels of Flexibility CHAOTIC Lack of leadership Dramatic role shifts Erratic discipline Too much change		
		Flexibly Disengaged	Flexibly Separated	Flexibly Connected	Flexibly Enmeshed	FLEXIBLE Shared leadership Role sharing Democratic discipline		
		Structurally Disengaged	Structurally Separated	Structurally Connected	Structurally Enmeshed	STRUCTURED Leadership sometimes shared Roles stable Somewhat democratic discipline Change when demanded		
		Rigidly Disengaged	Rigidly Separated	Rigidly Connected	Rigidly Enmeshed	RIGID Authoritarian leadership Roles seldom change Strict discipline Too little change		
Low		DISENGAGED	SEPARATED	CONNECTED	ENMESHED			
Levels of Cohesion		I - We Balance:		Closeness:		Loyalty:		
		I		I - We		We		
		Little closeness		Low - Moderate		Moderate - High		
		Lack of loyalty		Little loyalty		Some loyalty		
		High		Interdepend-		Interdepend-		
		dependence		ent		ent		
		independence		More indepenecce than dependence		High dependency		
				More dependence than independence				

## KEY

	Balanced
	Mid-Range
	Extreme



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## BIOGRAPHICAL SKETCH

Cheryl Lea Beverly was born in Tampa, Florida, on December 19, 1955. The second of four children, Cheryl graduated from Seminole High School in St. Petersburg in 1974. Cheryl received a B.A. in Special Education with an emphasis in specific learning disabilities from the University of South Florida in 1978. In 1987, Cheryl received a M.Ed. in Special Education-Interrelated Studies from the University of Georgia.

During the period from 1978-1989, Cheryl taught in special education classes in DeSoto, Broward, and Hernando Counties in Florida and Dougherty and Jackson Counties in Georgia. Her teaching experience included teaching students with mild to severe intellectual, emotional/behavioral, and learning disabilities. Although Cheryl has taught every grade level, the majority of her teaching experience has been in middle and secondary grades. From 1989-1991, Cheryl was the Child Find and Diagnostic Specialist for the Florida Diagnostic and Learning Resource System serving Hernando, Pasco, and Pinellas Counties in Florida.

While completing her doctoral studies at the University of Florida, Cheryl has served as a graduate teaching assistant and as a graduate research assistant in the Department of Special Education. She has also served as an instructor at the Penn State Great Valley Graduate Center in Malvern, Pennsylvania.

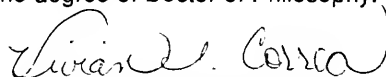
During her doctoral program, Cheryl was active in the Special Education Association of Graduate Students, serving as vice president and president. She also served as an editorial apprentice for the journal, *Teacher Education*



*and Special Education.* Not only is Cheryl a member of several subdivisions of the Council for Exceptional Children, but also she was actively involved in Division of Early Childhood subdivision. Cheryl is also a member of the National Association for the Education of Young Children and Phi Delta Kappa.

In the future, Cheryl plans to continue her research in the area of family involvement in education. Her other areas of research interest include education and the Human Immunodeficiency Virus, effective strategies for inclusion of young children with disabilities, and unified special education and regular education teacher preparation. Cheryl also plans to continue teaching at the university level.

I certify that I have read this study and that, in my opinion, it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.



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Vivian I. Correa, Chair  
Professor of Special Education

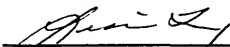
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Paul T. Sindelar, Cochair  
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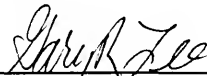
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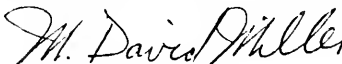
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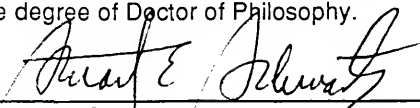
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M. David Miller  
Associate Professor of Foundations of  
Education

I certify that I have read this study and that, in my opinion, it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation for the degree of Doctor of Philosophy.

  
\_\_\_\_\_  
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This dissertation was submitted to the Graduate Faculty of the College of Education and to the Graduate School and was accepted as partial fulfillment of the requirements for the degree of Doctor of Philosophy.

August, 1995

  
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